



Invited to Participate?

An Ethnography of Patient Involving E-health in Heart Care

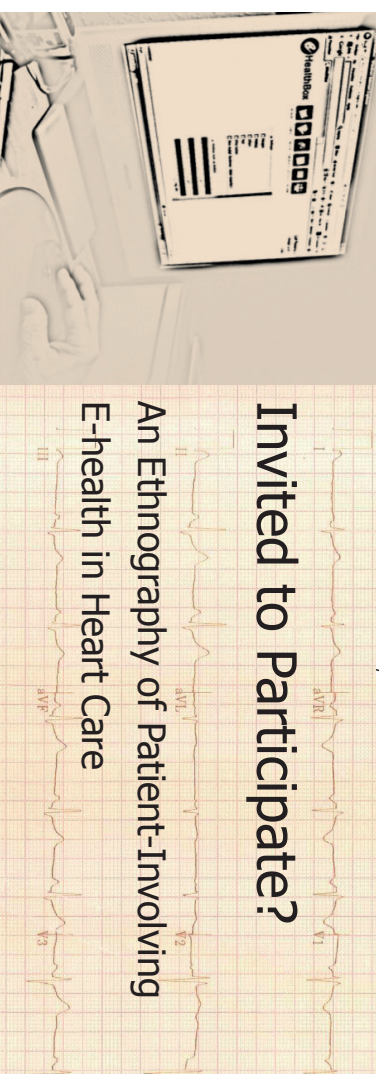
Nielsen, Karen Dam

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Karen Dam Nielsen

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Ph.D. Thesis

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An Ethnography of Patient-Involving E-health in Heart Care

KAREN DAM NIELSEN

Centre for Medical Science & Technology Studies (MeST)

Section for Health Services Research

Department of Public Health

University of Copenhagen

2015

Academic advisors:

Henriette Langstrup, Associate Professor, PhD (principal supervisor)
Centre for Medical Science & Technology Studies (MeST)
Section for Health Services Research
Department of Public Health
University of Copenhagen

Mette Nordahl Svendsen, Associate Professor, PhD
Centre for Medical Science & Technology Studies (MeST)
Section for Health Services Research
Department of Public Health
University of Copenhagen

Jesper Hastrup Svendsen, Clinical Professor, MD, DMSc, FESC
The Heart Center
Copenhagen University Hospital
& Department of Clinical Medicine
University of Copenhagen

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Summary

This thesis presents an ethnography of e-health and patient participation in heart care. Drawing on Science & Technology Studies (STS) and Computer Supported Cooperative Work (CSCW), the thesis goes beyond the common narrative of e-health as a solution and vehicle for transforming healthcare towards more patient-centered practices and explores *what patient-involving e-health, in practice, can become*. With the user test of an e-health system for ICD-patients as the pivotal case, the thesis unpacks what happens when patients are invited to become participants and, in particular, information providers through e-health as well as other devices. It does so from a highly interventionist approach where the author uses her role as facilitator of the user test to conduct an ethnographic experiment.

The thesis consists of four papers. Concurrently, but with different analytical devices, the papers point out how patient-involving e-health may reinforce existing challenges of establishing shared understandings between patients and clinicians of: 1) what constitutes relevant information in the context of care; and 2) how to interpret their mutual (communicative) responsibilities in order for care practices to be satisfactory and doable for both parties. The first paper situates e-health among established tools for involving patients as information providers in heart care and identifies central challenges associated with patient participation that may also apply to e-health. The second and the third paper show the specific challenges patients, and subsequently clinicians, encounter when engaging with an e-health system that is vested with multiple ideas about what patient participation involves. Each of these three papers proposes an analytical concept for opening up the workings of patient-involving e-health: ‘participatory scopic devices’, ‘dialogic filtration work’, and ‘participatory tactics’. In particular, these concepts add to the analytics of STS and CSCW for studying sociotechnical reconfigurations of healthcare. However, the concepts may also inform the wider field of research into e-health and patient participation. The fourth paper moves beyond the explorative research aim and translates the ethnographic insights from the user test into a design rationale for patient-involving e-health. The proposed

design rationale stresses analytical attention to the situated and diverging concerns among users and promotes iteration and negotiation as methodological cornerstones when designing e-health.

Overall, the thesis sheds light on some of the workings and implications of ‘participatory healthcare’ as it is promoted in and instigated by e-health. It points to the importance of clarifying – in design, policy-making and local practices – the invitations to participate that patients are given, while also recognizing that, in practice, participation will still be both unpredictable and unruly.

Dansk resumé

I denne afhandling præsenteres et etnografisk studie af e-health og patientdeltagelse i hjertebehandling. Med teoretisk afsæt i Science & Technology Studies (STS) og Computer Supported Cooperative Work (CSCW) sættes den typiske, løsningsfokuserede fortælling om e-health som 'driver' for et mere patientcentreret sundhedsvæsen i parentes. Spørgsmålet for denne afhandling er, hvilken type redskab patientinddragende e-health *bliver til i praksis*. Med udgangspunkt i brugertesten af et e-health system for ICD-patienter undersøger afhandlingen således, hvad der sker, når patienter i kraft af e-health eller andre redskaber inviteres til at deltage, i særdeleshed som producenter af information. Den metodiske tilgang er af et særligt interventionistisk tilsnit: med forfatteren som både facilitator og etnograf behandles brugertesten som et *etnografisk eksperiment med e-health og patientdeltagelse* snarere end en evaluering af et specifikt system.

Afhandlingen består af fire artikler. Artiklerne viser samstemmende, men med forskellige analytiske redskaber, hvordan patientinddragende e-health i praksis kan forstærke snarere end løse eksisterende udfordringer i interaktionen mellem patienter og klinikere. Dette gælder især udfordringer i forhold til at opnå en fælles forståelse af 1) hvad der er *relevant information* i en given behandlingssammenhæng, og 2) hvordan patienter såvel som klinikere bør fortolke deres gensidige ansvar i interaktionen. Den første artikel situerer e-health blandt etablerede praksisser i hjertebehandling for inddragelse af patientgenereret information og udpeger centrale udfordringer i disse, som sandsynligvis også vil gøre sig gældende for e-health. Den anden og den tredje artikel viser derpå de specifikke udfordringer, som patienter – og klinikere – oplever i brugen af et e-health system, som i sit design indeholder forskellige og til tider modsatrettede forestillinger om, hvad patientdeltagelse indebærer. Hver af disse tre artikler bidrager med et analytisk begreb for fremtidige studier af brugen af patientinddragende e-health, henholdsvis: ”scopende” deltagelsesteknologier’ (participatory scopic devices), ’dialogisk filtreringsarbejde’ (dialogic filtration work) og ’deltagelsestaktikker’ (participatory tactics). Disse begreber bidrager først og fremmest

til det fælles analyseapparat i STS og CSCW for studiet af sociotekniske omformninger i sundhedsvæsenet. Begreberne er dog også af relevans for det bredere forskningsfelt omkring e-health og patientdeltagelse. Den fjerde artikel går videre end det eksplorative forskningsmål og omsætter de etnografiske indsigter til et designrationale for patientinddragende e-health. Designrationalet understreger vigtigheden af en analytisk opmærksomhed på de situerede og ofte divergerende interesser blandt brugerne og foreslår iteration og forhandling som metodiske hjørnesten i e-health design.

Alt i alt belyser afhandlingen nogle af de dynamikker og implikationer, som et deltagende sundhedsvæsen indebærer, når deltagelse søges understøttet af e-health. Afhandlingen peger på vigtigheden af at skabe klarhed – i design, politisk rammesætning og lokale praksisser – omkring, *hvad* patienter inviteres til at deltage i og *hvordan*, samtidig med, at det anerkendes, at deltagelsespraksisser under alle omstændigheder vil være uforudsigelige og mangfoldige.

1. Introduction

Commonly, the narrative of e-health is a narrative of transforming healthcare through the design of information and communication technology (ICT) – or, in a more moderate version, a narrative of designing ICT for healthcare already in transformation. When speaking specifically of *patient-involving* e-health (the version of e-health with which this thesis is concerned¹), the envisioned transformation includes, above all, the role of patients. E-health unifies a number of patient imaginaries: patients as empowered partners; self-caring subjects; health consumers; lay experts; data producers; and – penetrating all of these – *active participants* (Felt et al 2009b; Finch et al 2008). Either through ambitious design intentions or by way of the broader public discourse on e-health and patient participation, all of these imaginaries become weaved into the invitations that e-health technologies pose to patient users. Likewise, a number of different benefits are ascribed to e-health: improved care, better clinical outcomes, and optimized use of sparse resources. In other words, with the overall narrative of e-health, patients are faced with a very comprehensive, yet also ambiguous, invitation to take part in their own treatment in new ways – implicitly, yielding increased agency and improved outcomes. Put shortly, this is an invitation to take part in better, more *participatory* healthcare practices. As a topic for social science, e-health thus brings with it the question of what participatory healthcare is and entails; e-health and patient participation together constitute a conundrum that is calling for attention.

More specifically, e-health typically invites patients to participate by *providing information* to fulfill multiple purposes, including qualifying clinical decision-making, enabling (or making up for) a reduction in face-to-face encounters, and improving patients' self-care. However, this invitation has repeatedly been shown to produce quite different practices and outcomes than expected, and few e-health technologies survive

¹ For the remainder of the thesis, I will use the term *e-health* in this narrow sense, that is, to denote patient-involving or solely patient-used ICT, thereby leaving out ICT for health professionals only. This definition of e-health, thereby, overlaps with terms such as 'telehealth', 'telemedicine', 'telecare' and 'm-health' – terms, that I have also broadly applied in my literature search. I will primarily use the term *e-health* when this is fitting, but when quoting or referring directly to studies or projects that apply other terms, I will in most cases use these for sake of recognizability.

their infancy (Murray et al 2011; Pols & Willems 2011; Tenforde et al 2011). Besides highlighting discrepancies between the promises and actual outcomes in concrete cases, this knowledge raises questions about the overall narrative of e-health and whether e-health is capable of unifying and realizing the manifold ‘future patient imaginaries’ and acclaimed benefits of participatory healthcare. Meanwhile, the ubiquitous participatory strategy in healthcare is persistent, as is the ambition to create e-health technologies that will carry it through, not least in a Danish context (Digital Sundhed 2008; Regeringen et al 2013b). Therefore, it is more topical than ever to ask: what does e-health *in effect* invite patients to?

This question is the point of departure for this thesis. To explore it, I look at the case of remote heart monitoring and, in particular, remote ICD-care², where e-health, in the shape of the web-application *P-Record*³, has been envisioned to facilitate improved information sharing through patient participation. ICD-care brings to the fore a number of characteristics of modern healthcare that are commonly perceived as highly challenging: distribution of care between different clinics; care being delivered remotely; and a rapid increase in the number of patients due to demographic changes, increased use of prophylactic treatment, and chronification of conditions owed to medico-technical developments. Adding e-health to the already technologically dense landscape of ICD-care in order to counter some of these challenges likewise reinforces the general narrative that e-health – and thereby ICT design – can be a solution to these problems. In P-Record, we thus find an exemplary case for exploring the question of what happens when patients receive a bold, materially embedded invitation to become information providers – an invitation that is invested with the comprehensive promise of participation and betterment.

During my research, it became clear that P-Record was not going to be a positive showcase for e-health as an enabler of participation. Rather, the case of P-Record affirmed the persistent lack of unequivocal success in the broader field of e-health and

² ICD patients are patients who, due to an underlying heart condition, have been equipped with an advanced pacemaker: an implantable cardioverter defibrillator (ICD), which monitors the heart and in case of life-threatening arrhythmias provides shock therapy.

³ The name P-Record is made up for sake of simplicity and used as a common denominator for various versions of the system. Other names for the system that appear in the thesis: 1) Participants in the user test got to know the system under the name ‘e-Healthbox’, 2) in Paper 4 P-Record is referred to as ‘myRecord’.

seemed to echo stories of failure (Greenhalgh & Russell 2010), unruly disturbance and reconfigurations (Dedding et al 2011), and an e-health revolution yet to come (Miller & West 2009). Studying the use of e-health and patient participation, crudely speaking, became a matter of exploring the production of expectations and the unfulfillment thereof – in e-health, at large, and among the specific users to whom P-Record posed an invitation to participate. This could easily lead to a research narrative of e-health as a failed strategy – a narrative of deconstruction and dismissal. Meanwhile, I have tried to maintain a perception of e-health as both a matter of *concern* and a matter of *fact* (Latour 2004). This implies that I have sought to critically interrogate the promise of e-health, while keeping in mind that the ascribed role of e-health within the discourse of healthcare transformation is so prominent and persistent, that shying away from attempts to qualify e-health design would be stopping short of the constructive research challenge at hand. Thus, with this thesis, I do not place myself as an outsider and spectator of the technology-centered transformation of healthcare. Rather, like the patients I have engaged with, I seize the invitation to take part in it.

From a common, democratically situated understanding, being invited to participate is inherently an invitation to be part of a shared project or activity, to interact with others, *and*, at the same time, to do so as an individual with a particular voice. Participation is thus a subjective endeavor within the framework of a collective project that poses a certain strategy, or structure, to the participants. In e-health, the participatory strategy materializes in the design of a given system. E-health use can thus be understood as responses to an invitation that are shaped by the interplay between *material arrangements*, *human interaction*, and *collective and individual projects*. Exploring this interplay, by zooming in and out of these three elements, is *my* response to an invitation to take part in the field of e-health. Overall, I pursue the question: *What happens when patients are invited to participate through e-health, and, specifically, how do Danish heart patients participate as information providers in remote monitoring practices?* My engagement with this question is shaped by some structuring conditions: the technology, sites, timeframe, and design-oriented project goal. My response is further shaped through: interaction with research participants; the practices studied; fellow researchers; and analytical perspectives. The latter also comprise the larger epistemic projects with which I engage: to understand and conceptualize the sociotechnical

arrangements of remote and participatory healthcare; the nature and implications of the *work* participants have to do to in these arrangements; and the *projects* that shape participation. Theoretically, this is an overall engagement with the overlapping fields of Science & Technology Studies and CSCW.

The aim of *my* particular project is twofold: to understand and to inform. I aim to progressively build a better understanding of: 1) the relationship between the material shape of the invitation to participate and how patients meet this invitation; and, 2) the implications of (materially embedded) invitations to participate for the organization of healthcare, including concrete encounters between patients and professionals. If this understanding is translated into recommendations for design and implementation, it may ultimately help qualify e-health innovation. Furthermore, it may inform a broader reflection on the participatory strategy currently guiding transformations of healthcare in Denmark and beyond.

The aim is operationalized in the following research questions. Each question guides one of the papers.

- How are patients invited and equipped to provide information in existing practices of remote heart monitoring; and what can we learn about the challenges of involving patients as information providers from these existing practices? (Paper 1)
- What kind of work does it require to participate as information providers with e-health; and how does this work affect how patients and professionals evaluate the specific tool? (Paper 2)
- How do patients, through e-health, respond to an overall invitation to become participating patients; and how do the ways in which they enact participation influence their experiences of the specific tool? (Paper 3)
- How can the local ethnographic insights into the ways in which P-Records' users responded to the invitation to participate be translated into recommendations for e-health design, in heart care and beyond? (Paper 4)

'Participation as it is inscribed into and practiced through e-health' is thus the conundrum around which my research revolves: what does participation mean and

imply – empirically, theoretically, and methodologically in my own research? In setting out to unpack this conundrum I approach participation, like I approach e-health, as a fluent category and object: what participation is depends on the situation. This also means that I do not depart from a normative celebration of participation and the derived ambition to identify barriers and enablers. Rather, I am interested in the practical and *normative variations* (Marres, 2012) in how patients choose to take part, or not, considering all variations as examples of meaningful ways that one makes sense and use of the invitation one is faced with. As a Danish social scientist recently put it when commenting on the ubiquitous imperative of participation in the Danish society and the associated framing of ‘lack of participation’ as a ‘democratic problem’:

The renunciation of participation is not necessarily the same as apathy, indifference, or exclusion. It does not have to be a sign of failure. The blank vote can express protest, wanting to participate on one’s own terms, or trusting that the better qualified will make a good decision.

(Silas Harrebye, in Information, 07.08.2014, my translation)

1.1 Overview of the thesis

The thesis is structured as follows:

Following this overview, I complete the **introduction** (Chapter 1) with an outline of the empirical context of my research (Section 1.2). While many of the issues touched upon in the thesis will apply to other clinical domains and geographical settings, there are also important particularities of remote heart monitoring and ICD-care and of healthcare innovation in Denmark. A short description of this empirical context and signposting of its relevant particularities for e-health is therefore needed upfront.

In Chapter 2, I present the **theoretical foundations** of the thesis. I do so by engaging with three different themes: *arrangements*, *work*, and *participatory projects*. These three themes constitute the dimensions of e-health that I progressively explore in the individual papers and thus form the overall analytical framework of my research. For each theme, I discuss the literature that has provided me with inspiration, starting by sketching core perspectives and key references, moving on to engage with the literature

from which I have adopted and further developed specific concepts. What emerges is an assemblage of concepts which together allow me to explore what e-health is; how it is used and with which implications; and which projects – individual and collective – e-health is part of.

In Chapter 3, I turn to the **methodological framework** of my research. Overall, the chapter addresses the special conditions, affordances and challenges of doing research ‘by invitation’ in a multidisciplinary innovation project oriented towards design and riddled with sometimes contradictory agendas. First, I present the occasion for my study: the overall research project behind P-Record, with a focus on the special research position the project offered me as facilitator of a user test. Informed by discussions in STS about intervention, as well as perspectives on the relationship between ethnography and design, I describe how I have approached the user test as an ‘ethnographic experiment’. I then present my fieldwork, with a focus on the user test and its heuristic benefits and challenges. In the final section, I describe my analytical process and my dissemination of results as yet still other ways of intervening.

Chapter 4 presents the **outcome** of my study. Here, I introduce the four papers on which the thesis builds and conclude on the shared contribution they comprise. First, I briefly describe how each of the four papers answers one of the research questions; the conceptual contributions they make; and the progression they afford through their order. The progression happens along two lines: 1) an analytical progression from sketching the field and setting a research agenda, through description and critique, to prescription, and 2) a temporal progression from exploring established practices, over experimenting with how these may change, to proposing a framework for future e-health design. I then take a step back and discuss how the papers come together as one research product, first by reviewing the synergies and frictions between the papers, then moving on to discuss the overall contributions and implications of the thesis and, subsequently, concluding on the overall research question I set out to explore.

Enclosed as **appendixes** are: written information about the research project for research participants; an instruction sheet for patient participants in the user test; and screenshots from P-Record.

1.2 Empirical context: ICD-care and e-health innovation in Denmark

Despite the wider clinical and geographical relevance of e-health and patient participation, this thesis is written within and about a particular context, namely ICD-care and e-health innovation in Denmark, and should be read as such. For this, an outline of this empirical context and its particularities in relation to e-health is necessary.

1.2.1 ICD-care: a telemedical and distributed care scheme

As most other Western countries, Denmark is undergoing significant demographic changes with a growing elderly population and an increased number of citizens living with chronic diseases. Adding to this, a wider span of treatment options has led to rising health expenditures and pressure on the allocated resources. (Danske Regioner 2011; Olejaz et al 2012) ICD-care is, in many ways, iconic for this development. The device itself is a piece of advanced technology that is constantly undergoing further technical sophistication (Afolabi & Kusumoto 2012), including development towards versions that are more sensitive, seamless, and personalized. This has contributed to making it a relevant and popular therapy in the treatment of cardiac disorders with documented life-prolonging effects, for patients with life-threatening arrhythmic disorder and, increasingly, as a preventive treatment for specific heart failure patients and survivors of cardiac arrest. In 2013, around 6,000 Danish citizens carried an ICD (Sundhedsstyrelsen 2014), with the official numbers varying according to which subcategories of cardiac devices that were included in the overall category of ICDs. Despite a current stagnation, the number of ICD-patients is expected to continue its overall growth as the range of indications upon which ICDs are chosen continues to expand (Petersen et al 2012; Sundhedsstyrelsen 2014).

An ICD is basically an advanced pacemaker. Once implanted into a patient's chest and wired up to the heart with 1-3 electrodes, it works by monitoring, pacing, and, if needed, giving shock therapy. It can be described as a rather invasive technology, with some studies suggesting associated psychological implications (discussed by e.g. Burke et al 2003; Pedersen et al 2009). Yet, it is also commonly framed as 'an extra life insurance' or 'like carrying the doctor under your skin', which gives 'peace of mind'

and sometimes provides exactly that life-saving treatment⁴. While ICD-care may become more and more common, it is far from being a mundane medical technology that can be handled anywhere. On the contrary, ICD-treatment involves a complex care scheme with many involved actors, sites, and supplementing technologies. In Denmark, six specialized clinics implant and monitor ICDs. These clinics follow the same national and international guidelines (Dansk Cardiologisk Selskab 2014; Brignole et al 2013) but, apart from that, organize ICD-care differently. Here, I describe the organization and practices of one of these clinics as they were shaped at the time of my fieldwork. At this particular clinic, patients are enrolled in regular follow-ups, typically every three months, where ICD-data is read and analyzed by specially trained technicians. This data includes cardiac events, the therapies provided by the device (pacing or shock), and the state of the device (e.g. battery level). In many cases, analyzing this data is a routine task, with no major remarks or actions to be taken, other than notifying patients that everything looks normal. In other cases, analysis may be tricky and the technician may consult a cardiologist who assists in interpreting the data and, if necessary, authorizes any needed action – for instance, an adjustment to medication or reprogramming of the device. Importantly, ICD follow-ups take place in two very different ways: *in-clinic* during a physical encounter between patient and technician (and if necessary, a cardiologist) and/or *remotely*.

Remote monitoring was first introduced in the early 2000s by the ICD-manufacturer, Biotronik (www.biotronik.de), shortly followed by Medtronic (www.medtronic.com). It has, since then, become a standard part of ICD-care, not least in Denmark, where an estimated 80-90 percent of ICD-patients are enrolled in the remote setup (Sundhedsstyrelsen 2014). These patients have been equipped with an extra device and a transmitter box, which receives data from the ICD-device (either wirelessly and automatically or by manual use, undertaken by patients) and transmits it to the clinic via a telephone connection and a data center managed by the ICD-manufacturer in question. In remote monitoring, data is either transmitted on scheduled dates in 3-month increments and on the patients' initiative (manual setup), or consecutively and automatically, for instance at a fixed daily time. In both versions, there is the possibility for the patient to initiate additional data transfers, in case they experience symptoms

⁴ Such framings were also articulated by both ICD-patients and clinicians during my fieldwork.

that they would like the clinics to evaluate. With manual or wireless remote monitoring, technicians only access the transmitted data on the scheduled dates for follow-up or, extraordinarily, at certain times of the day. The latter happens when either the patient or the system has transmitted data that causes an alert in the software program, which initially analyzes incoming isolated data, but cannot evaluate the patient's general status. While manual and wireless remote monitoring do involve different levels of patient participation that comprise a relevant research topic on its own (Bjørn & Markussen 2013; Grew & Svendsen n.d.; among others), the important distinction to note here is that between *in-clinic* and *remote* monitoring since this constitutes the specific empirical background for the development of P-Record, the e-health tool featured in this thesis.

For the majority of ICD-patients, who are remotely monitored, follow-ups do not include the possibility of talking to a clinician, and, therefore, patients are unable to explain symptoms, ask questions, and so on. Correspondingly, clinicians have to conduct the interpretation of the transmitted data without the possibility of obtaining additional information from patients, including descriptions of symptoms, information about relevant activities, bodily information, and the like. The physical absence of the patients frequently poses a challenge to making sense of data and also in conveying the outcomes to patients (Andersen et al 2011a; van der Velde et al 2012). In practice, this is often solved by phone calls; although this solution is a time consuming practice for clinicians who cannot always get a hold of patients (Simmers 2012). However, time is still saved for patients and the benefit from not having to travel to the clinic is often pointed out as one of the main reasons for the overall high satisfaction with remote monitoring (Petersen et al 2012; Costa et al 2010). As a telemedical arrangement, remote monitoring of ICDs thus involves both the typically acclaimed benefits *and* disadvantages of telemedicine. On the one hand, remote monitoring allows for a provision of healthcare across spatial and temporal borders, generally perceived as reducing the workload of the clinics and as making care more convenient for patients (Costa et al 2010; Ricci et al 2008), despite there being no consensus on the evidence for this (de Cock et al 2012). On the other hand, remote monitoring inhibit the monitoring of the patient's general clinical condition (Theuns & Jordaens 2012; Sundhedsstyrelsen 2014) and raises questions regarding clinical responsibility for and

interaction with ‘virtual ICD-patients’ (Theuns & Jordaens 2012). It is also generally acknowledged that remote follow-ups cannot stand alone, and they are, therefore, typically supplemented with annual or semi-annual in-clinic follows-ups.

Adding to the complexity of ICD-care, patients not only attend ICD-follow-ups at the specialized clinic, but also regularly attend medical follow-ups at the outpatient heart clinic of their local hospitals. The division of work between the device clinic and the outpatient heart clinics can roughly be described as a division between *monitoring devices* and *monitoring underlying heart conditions*, respectively. In practice, there are many overlaps between these clinical concerns and possible interventions, and collaborations between the device clinic and the local hospitals are, therefore, important. However, this poses a challenge: spatial, professional, and technical separation means that information does not travel smoothly between the clinics and decisions are not always aligned (Mønsted et al 2011). ICD-care, also in this respect, unearths a typical intersection of traits and challenges within modern healthcare and chronic care, in particular: the distribution and the potentially subsequent lack of coordination and continuity of care, with potentially great negative effects on the quality of care (Hofmarcher et al 2007; Bodenheimer 2008; among others).

1.2.2 E-health innovation in Denmark: welfare technology and user involvement

P-Record was envisioned as a reparative for the shortcomings of the distributed and telemedical setup of ICD-care by providing new opportunities for patients and clinicians to interact and for clinics to collaborate. The design process, final layout, and workings of the system will be described later (Chapter 3 and in each of the papers); my focus here is on the context in which P-Record was born. While comprising an attempt to improve communication and collaboration specifically in ICD-care, the system emerged through a broader, national e-health agenda that, during the last decade, has resulted in the (national, regional or local) funding of a number of innovation projects aimed at developing new technology-based health services in *chronic care* through *public-private partnerships* and *user involvement*. Each of these elements (in italics) link to the particularities of the Danish welfare society and predominant welfare discourses, and I will briefly outline the elements, one by one, focusing on these welfare links.

As the increasing number of citizens who live with a chronic disease is considered one of the main causes for rising health expenditures in the Western world (and increasingly in the developing world) (Bloom et al 2011), chronic care is a common subject for health innovation policies, including e-health. Within chronic care, e-health is often directed at ‘the big three’: diabetes, chronic obstructive pulmonary disease (COPD), and chronic heart failure (Pols 2010). This is also the case in Denmark, where the recent decade has seen a vast array of often publicly-funded projects that are targeted at reconfiguring care for these groups through technology – from small, implementation-oriented projects to large, national innovation programs⁵. With Denmark being a welfare society with a large public health sector and universal health coverage, the growing number of citizens living with chronic diseases and the subsequent pressure on the healthcare system is framed, here, as a welfare problem. Addressing the problem is, correspondingly, a central welfare task: that is, a societal endeavor led by state initiative and funding. Tellingly, e-health is in Denmark often referred to as ‘digital welfare’ (Regeringen 2013; Regeringen et al 2013a) or ‘welfare technology’ – a broad category for technologies that are, or are envisioned to be, part of the provision of classic welfare services, in particular healthcare and elderly care⁶. The term ‘welfare technology’ has been widely adopted as a policy term all over Scandinavia (Östlund et al 2014) that encapsulates three different, yet interlinked, capacities that these technologies are envisioned to have. Firstly, ideally, they enable the provision of welfare services in more cost-effective ways, thereby contributing to the sustainability of the welfare system. Secondly, they facilitate or further welfare for the individual citizen (e.g. a patient with a chronic disease). Thirdly, policy-makers envision welfare technologies as indirect vehicles of welfare by comprising business ventures and export products that create jobs and, ultimately, tax revenues – thereby, securing the economic foundations

⁵ For examples of recently or currently running large-scale projects, see, for instance: www.levvel.dk, www.partnerskabetunik.dk, www.patient@home.dk, www.opilab.dk. It is outside the scope of this thesis to offer an overview of the numerous projects that have seen daylight over the past decade. A dynamic national map of telemedical projects (not all public-private partnerships) is provided by Medcom: <https://medcom.medware.dk/tm/kort>. (All links accessed October 31, 2014)

⁶ Many different definitions of ‘welfare technology’ are given. See for instance: www.welfaretech.dk/om-os/om-velfaerdsteknologi (accessed October 31, 2014).

of the Danish welfare system, with the – in this context – side-effect of helping to solve welfare-related challenges abroad (Danske Regioner 2010a)⁷.

This latter, explicitly fiscal focus of the Danish – and Scandinavian – welfare-technology agenda also largely shapes innovation processes in, for instance, publicly funded e-health development. This leads me to the second characteristic of the broad Danish e-health agenda: the emphasis put on public-private partnerships. While public-private partnerships is a contested issue and far from a standard in the Danish public sector (Vrangbæk 2008), involvement of private, often industrial, partners has become a strategic focus of many innovation initiatives, especially in healthcare and elderly care (Danske Regioner 2010b; Weihe et al 2011). The private partner is typically meant to contribute the technical skills and production infrastructure needed to bring about concrete products and to potentially bring them to a larger market. In return, the private partner benefits from research, and the knowledge basis and living labs of the institutional partners – and at times more direct financial subsidies. Danish e-health innovation, thus, widely builds on the positive view of public-private partnerships as “*a way to bring private sector expertise and civil society enthusiasm into the delivery of public services*” (Vrangbæk 2008:142) or as contributing to that strengthening of the private sector that is perceived as a premise for sustaining welfare (cf. the ‘fiscal’ vision of welfare technology).

However, the partnership model in e-health innovation is not only a framework for public-private ventures, but also involves an emphasis on involvement of all stakeholders, including citizens, as potential users. Terms such as user-centered, user-driven, and participatory seem almost mandatory in Danish innovation policies and project descriptions, not least in e-health innovation, where user involvement comprises both a desired outcome and an intricate part of development processes. This ubiquitous emphasis on user involvement echoes that of other countries and contains a well-described unification of (or rather tension between) technocratic and democratic rationales (Martin 2008; Kensing & Greenbaum 2012). In the former, user involvement is perceived as an instrument for qualifying innovation and ultimately enabling, in this case, Denmark, to “*provide superior products and solutions*” (Ministry of Foreign

⁷ For an example and discussion of global dissemination of Danish health technologies, see Nielsen & Langstrup 2014.

Affairs of Denmark, n.d.:1). In the latter, user involvement is ascribed democratic values. First of all, public innovation is perceived to gain its legitimacy through citizen involvement, as citizens are not only the end users but also key stakeholders in any innovation in the public sector, because they are part of the ‘public interest’ (Jæger 2011). Second, as a more local democratic value, is the idea that people have the right to be included in defining the practices they are part of and to achieve ownership of the changes that a specific local setting undergoes. This idea has been articulated and furthered by Scandinavian workplace studies aimed at facilitating participatory innovation processes with collaboration between staff and management (e.g. Bansler 1989; Greenbaum & Kyng 1991; Schmidt 2000), prominently represented by the field Participatory Design (Clemensen et al 2007; Kensing 2003; Kensing & Blomberg 1998; Sjöberg & Timpka 1998). Participatory Design has gained worldwide attention but, for good reasons, continues to thrive ‘at home’ in Denmark and its neighboring countries with similar welfare systems, big public sectors, and a tradition for civic engagement.

As a publicly financed research and innovation project, the project behind P-Record, Co-constructing IT & Healthcare (CITH)⁸, was born out of this overall e-health agenda and tapped into its main elements: targeting chronic care, stressing private-public partnership, and promoting user-involvement, all in the name of sustaining or creating better welfare. It, thereby and overall, followed in line with a number of similar small-scale projects. Some of these have resulted in long-term implementation of devices, as some of the earlier telemedical projects, while others live on in new project formats⁹. At large, e-health remains exactly an *innovation* agenda with a myriad of projects and local solutions and persistent political ambitions to make e-health a part of standard healthcare services (Danske Regioner 2012; Digital Sundhed 2008; NSI & Sundhedsstyrelsen 2012; Regeringen 2014), yet this ambition remains far from achieved. Only in the broader field of ‘digitalization of healthcare’ may Denmark rightfully claim to be among the forerunners: electronic patient records and a national digital entrance to the healthcare system have, indeed, become standard. At a recent

⁸ See the project website: www.cith.dk (accessed December 16, 2014).

⁹ An example of the former is the Telekat project (www.telekat.dk); an example of the latter is the UNIK project (www.partnerskabetunik.dk) (both websites accessed December 16, 2014).

national conference¹⁰, which brought together policy makers, practitioners, researchers, and industry, presentations and discussions echoed those of the previous years with the continuous call for coordination and standardization of e-health solutions and efforts. Yet, this call was given even more weight and reframed as the prime focus of innovation by several speakers, who in concert advocated for shifting the focus in e-health from device to service innovation.

Thus, the case of P-Record is, in many ways, iconic for the current Danish e-health agenda. The system was developed in order to *improve both the quality and efficiency of care* for a group of *chronically ill* patients and through a *public-private partnership* committed to *user-centered design* and, finally, orientated towards *service rather than device innovation*.

¹⁰ E-sundhedsobservatoriet Annual Conference 2013, Nyborg, Denmark. <http://2013.e-sundhedsobservatoriet.dk> (accessed December 16, 2014).

2. Theoretical framework: understanding e-health and patient participation

Where e-health in the political discourse of health and innovation is promoted as a rather singular entity, theoretically I will depart from the basic viewpoint that *e-health does not have an inherent identity*, neither as field nor specific technology. Rather, what e-health is shifts between contexts and situations and through ongoing processes of reinterpretation and negotiation, as has been convincingly demonstrated in the field of STS (Petersson 2014b). This functions as both an ontological and epistemological premise in my research.

First of all, this means that my research interest in e-health is precisely fuelled by e-health's ontological fluidity (Moreira 2000); that is, the way e-health is made into a solution for a broad range of problems – each problem defining e-health as a specific kind of solution accordingly. E-health is, for instance, framed as: a tool for reaching beyond the clinic and delivering *care at a distance*; a tool for *increased information flow* and better clinical-decision making; a tool for *self-care* and independency; and an *empowerment* tool for patients as partners and consumers in healthcare. All of these visions of e-health often interweave and further build on the same underlying goal of “*ease(ing) the tensions (...) between providing high-quality service and simultaneously trying to contain costs*” (Petersson 2014a:153, paraphrasing Blomqvist), yet they also comprise important normative and practical differences which do not always align. Moreover, when put into use, e-health may be remade into yet other kinds of solutions, as users in different ways adapt the devices to their own projects and practices (Pols 2010; 2012).

Secondly, fluidity also defines e-health as a research object. Depending on the analytical filter one applies when studying e-health, it takes a certain form. One can, for instance, study e-health as a design object (Storni 2013), political project (May et al 2005), combined product and market (Parente 2000), organizational issue (Murray 2011) and everyday practice (Langstrup et al 2013) – and as various subcategories under these labels. Recognizing this multiplicity, I first of all understand e-health as situated

sociotechnical arrangements in which different versions of what e-health is are negotiated and merged. This filter provides an inclusive, yet also distanced perspective on e-health. In order to unpack the workings and implications of particular e-health arrangements, further analytical filtration is needed. I choose my ‘filters’ as a result of an interest in exploring one particular version of e-health: namely, as a vehicle and solution for an overall participatory transformation of healthcare – as a *participatory* tool. Accordingly, I approach the use of e-health as participatory practices. To unpack these participatory practices, I look at three dimensions: the specific sociotechnical *arrangements* they are embedded in; the *work* they involve; and the *participatory projects* they are guided by and invoke. Zooming in on each of these dimensions ultimately allows me to inquire into the often noted discrepancy between the positive vision of e-health and the practical experiences of users (e.g. Miller & West 2009; Oudshoorn 2011) and understand it as different interlinked problems: complex sociotechnical arrangements and the shortcomings of their scripts; dynamics of the communicative work involved; and divergent projects guiding users.

The following presentation of my theoretical framework is structured according to these three dimensions: arrangements, work, and participatory projects. This structure represents a progression through my research questions, with each part discussing the literature that has provided the main inspiration for one of the papers accordingly. The structure also, roughly, represents a journey from the center to the periphery of what I consider my theoretical home ground: Science & Technology Studies (STS) and the closely-related field, Computer Supported Cooperative Work (CSCW). In the process, I engage both with the innovation-oriented literature that significantly characterizes the field of e-health and patient participation, and the more descriptively oriented literature that has formed alternative narratives of e-health, to which I seek to contribute. What I gradually arrive at is an overall proposal to direct attention towards the resources patients draw on when responding to an invitation to participate with e-health and what these resources create, such as expectations, overflows, and resistance. I propose three conceptual tools, summarized as: *participatory scopic devices*, *dialogic filtration work*, and *(material) participatory tactics*.

2.1 E-health as arrangements

E-health is often understood as a vehicle for transforming healthcare. This definition grants technology significant, pre-programmed agency which may be rightfully questioned (Akrich 1992; Pinch & Bijker 1984). Yet, it also draws our attention to e-health being more than technology: e-health is part of the larger (re-)organization of healthcare. Acknowledging the relation between technology and social practices, I overall approach e-health as *arrangements*. This leads me to the question of what *kind* of arrangement e-health, and in particular P-Record, can be described as? Importantly, every answer is performative and can, in that sense, be instrumental. In the following, I engage with three overall answers: first, an innovation-oriented answer understanding e-health as *vehicle for transforming* healthcare; second, a material-semiotic answer that questions this rather deterministic approach by underscoring the *sociotechnical interdependencies* of e-health; and third, answers describing the specific sociotechnical arrangements of *heart monitoring* that P-Record is to be part of. This engagement ultimately leads me to propose my own (instrumental) answer as to how we might understand the arrangements of e-health in heart care.

2.1.1 E-health as vehicle for transforming healthcare

E-health is a commonly featured topic in an extensive body of innovation-oriented literature that deals with the transitions that are currently taking place in Western healthcare sectors. This is a body of literature that, despite spanning very different disciplines and perspectives, at large, takes demographic changes, increased chronification, and sparse resources to form an emergent problem to which a move towards more patient-centered and technologically mediated practices can be a solution (Chavannes et al 2012; Cowie et al 2013; Kaelber et al 2008). This problem-solution narrative, which make e-health a *vehicle* for the facilitation of patient-centered healthcare (Finch et al 2008), has also become standard in the Danish context with healthcare policies and research recurrently granting patient-involving technology a prominent role in future healthcare (Regeringen et al 2013b; Pedersen et al 2011; Olejaz et al 2012). E-health is also increasingly framed as a vehicle for what has been labeled the 4P's of future medicine: prediction, prevention, personalization, and participation (Hood 2013; Meier et al 2013; Swan 2012).

Medical informatics is among the innovation-oriented fields that tap into and further fuel the narrative of e-health as solution and vehicle for transforming healthcare in the face of demographic change and the associated economic, organizational, and clinical challenges (Archer et al 2011; Eysenbach 2008; Koch 2006; Mihalas 2014). The tone is generally optimistic, with regards to both the transformative power of e-health and the extent to which this can be determined by design; studies often depict a rather linear relation between the design intention, a thorough and reflexive design process aimed at securing optimal functionality and usability, and the subsequent use – and value – of a certain technology (e.g. Das & Svanæs 2012; Morrison et al 2012). Misfits are often ascribed to formal implementation barriers, such as regulatory issues (e.g. Silverman 2003), lack of interoperability between different systems (e.g. James 2005), and access limitations (e.g. Miller & West 2009). Also design studies that approach technology as service design (Holmlid 2009; Stickdorn & Schneider 2010) frame e-health as ‘solution and vehicle’ for a certain kind of change, as in the case of the project behind P-Record (Andersen et al 2010a; Moll 2010). However, in a service design approach, technologies are not thought to automatically bring about the desired change; they have to be accompanied by careful reorganization of practices to enable the provision of entirely new and *dynamic* services in which value can be collaboratively created. E-health design is, thus, explicitly about building arrangements rather than applications in order to achieve the envisioned effects or *value* (Andersen et al 2010a; Moll 2010).

The generally high hopes invested in e-health, whether from application-centered or service-design approaches, do not mean that the lack of evidence of the envisioned effects is overlooked: a recurrent theme is indeed the fact that the clinical and/or economic efficacy of patient-centered e-health has proven hard to demonstrate (Archer et al 2011; Ekeland et al 2010; Miller 2007; Shah et al 2008; Tenforde et al 2011). However, this has not significantly shattered the vision of e-health as a solution and vehicle for the betterment of healthcare practices under pressure; on the contrary. More evaluations that identify barriers and benefits are called for – with the overall aim of informing smarter design or support decisions of implementation (Ekeland et al 2010; Law & Wason 2014). Thus, the view that e-health *can* be fitted to provide particular outcomes (if the organizational issues impeding successful implementation are overcome), is persistent in a large part of the innovation-oriented literature on e-health.

Meanwhile, there also seems to be a growing awareness that there is a more unruly side of the transformative power of e-health. Several, still innovation-oriented, authors have thus stressed the role of ongoing mutual adaptation between technologies and the social and organizational practices they are to be part of and subsequently called for implementation studies that take the dynamic social appropriation of e-health into account (Ball & Lillis 2001; Ekeland et al 2010; Hess et al 2007; Lemire 2010; Mair et al 2012; Murray et al 2011).

Others advocate a more radical move away from evaluations of e-health that focus on efficacy and barriers (Finch et al 2003; Greenhalgh & Russell 2010; May et al 2006; Pols & Willems 2011). The workings of e-health simply seem to be impossible to identify and account for in evaluations that depart from an understanding of e-health as ‘solution and vehicle’ for a specific transformation of healthcare. As Pols (2012) has pointed out in relation to telecare technologies, evaluation methodologies that target stable research objects in controlled environments and look for predefined outcomes are of little use when studying the introduction of complex technological arrangements into messy everyday life settings. Such interventions are simply impossible to keep stable (p.13).

2.1.2 E-health seen through a material-semiotic lens

On this backdrop, Science and Technology Studies (STS) offer an alternative framing of e-health that allows us to go beyond the ‘solution and vehicle’ approach to e-health, and explore the workings and implications of e-health that tend to escape efficacy evaluations. Looking through an overall material-semiotic lens, STS scholars have approached e-health (in STS research most commonly referred to as telemedicine or telecare) as *sociotechnical arrangements* or *networks* (e.g. Aceros et al 2014; Langstrup 2008; Langstrup et al 2013; Oudshoorn 2011; Schillmeier & Domènech 2010) – that is, as more or less fluent assemblages of mutually constituent human and non-human actors. The material-semiotic lens bears on actor-network theory (ANT), primarily developed in key works by Latour (1987; 1993), Callon (1986) and Law (1994; Law & Hassard 1999), and its symmetrical analysis of human and non-human actors and the networks they form. Importantly, it is through these networks that actors, whether we speak about objects or people, are “*made to act*” (Sismondo 2010:82) – no actors can

act independently of the relations that they are part of. This makes the *relations* between actors the prime analytical object. Thereby, a material-semiotic approach basically implies an understanding of e-health as more than a series of isolated technological devices. As an example, while the name P-Record refers to a specific application, this application only comes into use and effect *as e-health* through a number of relations between people, practices, institutions, artifacts, and so forth that make up the context of use.

At first glance, this view echoes the vision of e-health as contributing to a transformation of healthcare by fundamentally reconfiguring healthcare practices and the division of roles and responsibilities between patients and professionals, whether ‘automatically’ or as part of active reorganization through service design. However, a material-semiotic approach implies more than just emplacing technologies as instrumental agents in larger organizational networks; importantly, it underscores complexity and *interdependency* as an inherent part of sociotechnical arrangements (Schillmeier & Domènech 2010) and thus grants technologies like e-health more volatile, socio-cultural agency (Oudshoorn 2011). As such, a material-semiotic approach challenges the deterministic and instrumental view of technology that still characterizes the wider field of e-health innovation (as also noted by Oudshoorn 2011:18). As relational phenomena, e-health technologies do *not* carry an inherent identity, e.g. as driver for patient empowerment or shared decision-making; although e-health technologies present their users with such scripts (Akrich 1992), these do not determine use. Rather, what a certain e-health technology (or service) is, is negotiated and shaped through practice. Conversely, no existing practice is left untouched by the adaption of technology; any new technology disrupts practices and opens a space for renegotiating these – at least momentarily. Therefore, predefining outcome variables makes little sense. Once implemented, e-health may produce completely unforeseen and unruly effects, as it has repeatedly been demonstrated by STS scholars (e.g. Langstrup 2008; Lehoux et al 2004; Nicolini 2006; Pols & Willems 2011). Rather than being a process of transmitting ready-made tools and services to instigate the intended transformation, implementing e-health is a process of reconfiguring, reworking, and reinterpreting (Mort & Smith 2009) the use of a given technology and what constitutes good care (Oudshoorn 2009; Pols 2010; Roberts et al 2012). In ANT-terms,

implementation of e-health is an ongoing process of *translation* (Callon 1986; Latour 2005) of the specific device as well as all other elements in the emerging sociotechnical arrangement.

By understanding e-health as sociotechnical arrangements, I, thus, take a perspective that may diverge from prevalent policy and research perspectives on e-health in its analytical goals, resources and effects, but that actually takes seriously the common perception of e-health as transformative. As envisioned, innovation of e-health has indeed lead to the emergence of new sociotechnical “*care infrastructures*” (Langstrup et al 2013:47), where both old, new, and ‘odd’ technologies constitute vital links (Langstrup 2005; Danholt & Langstrup 2012) and in which roles and tasks are redistributed between home and clinic, fundamentally transforming the clinical encounter (Bruni & Rizzi 2013; Finch et al 2008; Lo & Parham 2010; May 2007; May et al 2006; May et al 2005). Only, transformations rarely happen in the intended ways or with the hoped-for outcomes in terms of clinical and economic efficacy. Thus, it makes more sense to conceptualize the establishment of e-health arrangements as *alterations* of rather than solutions in healthcare (Zuiderent-Jerak 2010).

Moving from understanding e-health as a specific kind of solution to approaching e-health as a set of complex and fluent sociotechnical arrangements is my first step in establishing a productive analytical framework. Compared to the predominant innovation-centered e-health research, this is basically a move from a focus on designing and evaluating the efficacy of specific transformations associated with e-health, to studying the ontology of these. Importantly, as Hanseth et al (2004) has pointed out in relation to how ANT may benefit Information Systems research (IS), a material-semiotic approach does not stand in opposition to innovation-oriented approaches. On the contrary, it can support the orientation towards organizational aspects and effects of for instance e-health by facilitating “*a better understanding of the interaction between the social and the technical system*” (Hanseth et al 2004:117).

2.1.3 Heart monitoring arrangements: surveillance, cyborgs and scopic media

My second step in establishing an analytical framework for studying e-health is to get more specific. What kind of sociotechnical arrangement can patient-involving e-health

in ICD-care and other heart monitoring practices be understood as? Which capacities may we single out as defining?

Heart monitoring arrangements have often been analyzed as technologies and practices of *surveillance* that extend the clinical gaze outside the physical location of the clinic (Dubbel 2006; Laviolette & Hansson 2007, Oudshoorn 2009; Oudshoorn 2011)¹¹. In describing telemonitoring as surveillance, STS scholars have stressed two ways in which these arrangements differ from the panopticon-like surveillance modeled by Bentham, later analyzed by Foucault (1977), and consecutively reproduced in popular and academic discourse, although often with much less nuance than what Foucault provided, as pointed out by Gad & Lauritsen (2009). Firstly, rather than purely constituting systems of control and oppression, telemonitoring in heart care (and healthcare more broadly) involves what Lyon describes as *caring* surveillance (2001) that is potentially beneficial to patients as it can provide safety, new forms of proximity (Oudshoorn 2009), and/or empowerment (Laviolette & Hansson 2007). Secondly, telemonitoring is a decentered form of surveillance, where the clinical gaze is not only extended to include the homes and everyday lives of patients, but also includes patients as inspectors and observers (Oudshoorn 2011).

These moderations point to the limitations of conceptualizing telemonitoring as arrangements of surveillance, and the authors referred to above subsequently propose alternative, yet still closely related conceptualizations. In their study of home monitoring in heart care, Laviolette & Hansson (2007), drawing on Mann (2004), argue for a closer analytical attention to the distinction between surveillance and '*sousveillance*', the latter referring to the inverse surveillance 'from below' where people use monitoring devices such as cameras to observe authorities or record their own experiences (Mann 2004). Adams (2010) likewise applies the notion of *sousveillance* (and the related notions of '*coveillance*' and '*infoveillance*') in relation to online patient ratings of healthcare providers; Adams has further suggested to stick to the root '*veillance*' to stress that monitoring practices in healthcare often involve surveillance 'from nowhere' (Adams 2014). More interesting in relation to telemonitoring is perhaps the concept of '*oligopticon*' (Latour 2005:181), proposed as a

¹¹ In relation to telemedicine broadly, Sinha (2000) has introduced the notion of 'virtual gaze' as a modification of Foucault's (1977) notion of 'clinical gaze'.

more suitable metaphor than the *panopticon* for surveillance technologies in healthcare by Albrechtslund & Lauritzen (2014). Following Latour, oligoptic surveillance is specific rather than general: the observer only sees what is in focus – what is irrelevant or outside the scope is rendered invisible. Moreover, an oligopticon is never stable or automatic (it is not an inherent capacity of a given technology), but instead relies on the cooperation between people and technologies to enable relevant surveillance. With this lens, monitoring technologies in healthcare are reframed as potentially productive, but also as very fragile arrangements of surveillance (Albrechtslund & Lauritzen 2014:212).

These reconceptualizations all serve to underscore the distributed agency in monitoring arrangements in healthcare, including the active role of patients in ensuring an extended clinical gaze. In the specific context of ICD-care, others have concurrently stressed how patients are never passive objects of monitoring, despite promises of remote ICD-monitoring as granting patients independence by ‘leaving them out’ as much as possible (Bjørn & Markussen 2013:21). In practice, ICD-patients are heavily dependent on the monitoring infrastructure – and this infrastructure, in return, depends on their cooperation, e.g. in taking care of and staying close to the transmitter box (Bjørn & Markussen 2013). Underscoring these interdependencies, ICD-patients have also been conceptualized as cyborgs (Grew & Svendsen n.d.; Bjørn & Markussen 2013), referring to the seminal work by Haraway (1990; 1991). ICD-patients, these authors suggest, are truly cyborgs in the sense of being bodies that are deeply entrenched in relations to – in fact, indistinguishable from – machines, data, scientific knowledge, and larger sociotechnical communities.

Inspired by these different conceptualizations and the insights they have produced, but also recalling their limitations, I propose to understand the sociotechnical arrangements of remote heart monitoring as ‘*scopic*’ arrangements (Cetina 2003; 2009). The notion of scopic arrangements brings forth the capacities of heart monitoring as fragile sociotechnical arrangements specifically aimed at letting certain information in and leaving other out and, thereby, delimiting a relevant clinical gaze – or *scope*. Departing from classic symbolic interactionism and the key notion of interaction order (Goffman 1983), Cetina’s analytics is fitted for studying the increasingly ‘synthetic’ and global forms of interaction afforded by ICT (Cetina 2009). From the outset, Cetina’s approach

is descriptive more than critical and, as such, differs from the above-mentioned surveillance and cyborg approaches that conspicuously address themes like power, control, emancipation, and posthuman figuration. Nonetheless, Cetina's analytics also point out possible problematic issues in 'synthetic interactions'. One of these regards how interactional partners can be said to be in each other's presence when meeting 'in time rather than place' or interacting entirely globally and asynchronously. Redefining Goffman's concept "*response presence*" (Goffman 1983:2) as "*an accountability for responding, not physical presence*" (Cetina 2009:69), Cetina directs attention to the question about which responsibilities interactional partners can be said to have for responding to one another in synthetic situations, as for instance in remote heart monitoring.

In Paper 1, I draw on Cetina to propose an inclusive, yet specific, denominator for heart monitoring arrangements – inclusive, since it focuses on capacities rather than technical properties and thus allows me to analytically align otherwise different devices and practices of heart monitoring; and specific, since it points to the core (intended) capacity of heart monitoring arrangements: *scoping*. In these scopic arrangements, involvement of patients is both inevitable and crucial. Therefore, I suggest conceptualizing the technologies that are part of the scopic system of heart monitoring as *participatory scopic devices*¹². This conceptualization allows me to inquire into the role of patients in different heart monitoring arrangements, asking what we may learn from existing practices in heart care about challenges and implications of involving patients as information providers – the topic of Paper 1.

2.2 E-health as work

Having framed my research object as participatory devices in the scopic arrangements in heart care, I now turn to how I approach the practices that help make them work as such. These practices are *use practices*, but if we are to acquire a deeper understanding of their ontology, we need a more specific and productive conceptualization. Following the overall sociotechnical approach sketched in the previous section, technology use is never a simple matter of following a script and, thereby, realizing the intended function

¹² I will elaborate on the notion of participatory devices (Marres 2011) in Section 2.3, when I lay out my analytics for understanding the participatory projects intertwined in e-health and heart monitoring.

of certain device, neither so is e-health and other participatory scopic devices in heart care. Paraphrasing Nicolini (2006), when I study the use practices of P-Record, I thus inquire into ‘the work it takes to make P-Record work’ and, thereby, tap into a body of literature within the overlapping fields of STS and CSCW that has pointed out the invisible work involved in telemedical practices (Langstrup et al 2013; Oudshoorn 2008; Pols 2012; Roberts & Mort 2009, among others). Inspired by interactionist accounts of the intricacies of information production in healthcare and building on dialogic communication theory, I explore how a focus on invisible work can be attuned to grasp the specific characteristics of patients’ work as information providers through e-health. In doing so, I infer the significance of interpersonal and communicative aspects in the workings of sociotechnical arrangements.

2.2.1 The (invisible) work it takes to make technologies work

In turning to the concept of work, I do not move far away from the empirical context. P-Record was the result of a design research project committed to CSCW, among other approaches, and the derived ambition to design ICT to support the existing invisible work of ICD-patients in acting as diagnostic agents (Oudshoorn 2008) and information couriers bridging interinstitutional care (Unruh & Pratt 2008) (Andersen et al 2011a; Bjørn 2010; for a similar design ambition, see also Piras & Zanutto 2010). Speaking of *patients’* work represents an extension of the empirical field of CSCW-studies and design from formal healthcare settings and professional practices to the home and patients’ everyday life with illness (Reddy et al 2010). This move has been criticized, on the one hand, for emptying out the meaning of the concept work and consequently making the phenomenon that CSCW is fitted to study disappear (Schmidt 2010) and, on the other hand, for potentially involving a problematic transfer of workplace values such as efficiency and productivity into other spheres along with the introduction of CSCW-design into these (Gaver 2001). However, this move is, as the design of P-Record demonstrates, an empirical reality making the concept of work ‘native’ for my study of e-health. Moreover, CSCW is not the first field to employ the concept of work in relation to patient practices: the same symbolic interactionist roots that CSCW builds on (Corbin & Strauss 1985; Strauss 1985) have long inspired medical sociologists to study the way people live with illness as involving different kinds of work (Conrad & Bury

1997) – at times, in combination with a sociotechnical perspective, which makes the concept of work not just an empirically native but also analytically relevant concept for me to engage with.

STS-studies of e-health and telecare have been particularly committed to analyzing *patient work*, as well as the informal work of health professionals, here in relation to making sense and use of new technologies and with an emphasis on this work as often invisible (e.g. Bruni & Rizzi 2013; Mort & Smith 2009; Oudshoorn 2008; Pols 2012; Roberts & Mort 2009). The concept of invisible work was introduced by Star & Strauss (1999) in order to highlight the deeply contextual nature of the concept of work and how the perception of ‘what counts as work’ in a particular context, for instance healthcare, renders some forms of expertise, activities, or groups of actors invisible. Following CSCW’s interest in “*the tension between formal task descriptions and overt work on the one hand, and informal tasks and ‘behind the scenes’ work on the other*” (Star & Strauss 1999:9), they argue for the value of inquiring into the situated processes through which some forms of work are *made* visible and others are relegated to the back, particularly when studying ICT to support cooperative work. Showing patients’ – and professionals’ – use of e-health as involving *invisible* work often serves as a critical perspective on the common promises of e-health (and, more broadly, telemedicine and telecare) as replacing existing work. Rather, e-health redistributes work. E-health may redistribute work from professionals to patients, as demonstrated by Langstrup et al (2013) in the case of a telemedical solution in heart rehabilitation where patients had to produce data and observations otherwise done by nurses. Or e-health may redistribute work from one professional group to another, as Oudshoorn (2011) demonstrates in the case of a telemonitoring service in heart care where a new group of telemonitoring workers took over tasks related to monitoring *as well as* care from the prescribing clinics. In such processes of redistributing work, certain types of work are often rendered invisible, like, for instance, telemonitoring workers’ care work (also described by Roberts et al 2012) or patients’ work of producing data (Oudshoorn 2008; Langstrup et al 2013). Entirely new types of work may also emerge, which are easily overlooked and rarely articulated in protocols and product descriptions, such as the *instruction work* needed to make patients users of telecare devices (Oudshoorn 2008) or the

domestication and *maintenance work* patients have to undertake in order to make devices fit into and function in their everyday lives (Langstrup 2005; Pols 2012).

Pointing out these activities as indeed *work* serves the political purpose of making them visible and acknowledged as crucial conditions for making e-health and telecare work. Subsequently, this process of making work visible often also helps to shed light on the persistent failure of these kinds of technologies in clearly delivering the hoped-for cost- or time-reducing effects, let alone in being smoothly implementable and sustainable. Making work visible may, however, also involve tradeoffs (Suchman 1995) such as counterproductive formalization and standardization. As Star & Strauss (1999) underscore, inquiring into the relation between visibility and invisibility in the specific context, inevitably changes these relations. The possible pitfalls of making work visible are also relevant to recall in the case of e-health. For instance, while Roberts et al (2012) to some degree advocate formal support and systematization of telecare workers' informal care work, formal recognition may indeed also impede this work if it means increased surveillance, bureaucracy, and ultimately less room for tailoring care to individual patients/citizens, as has been shown in examples of efforts to make work visible in nursing (Bowker et al 1995; Wagner 1995, as discussed by Star & Strauss 1999).

The notion of invisible work is closely tied to the notion of '*articulation work*' (Strauss 1985; Schmidt & Simone 1996), labeled as CSCW's core conceptualization of work (Schmidt 2010) – a key to understanding how people succeed (or not) in coordinating their activities in collaborative work situations. As an analytical tool for CSCW, '*articulation work*' serves to explore in order to intervene into cooperative work practices and "*enhance the ability of cooperating actors in articulating their activities*" (Schmidt & Simone 1996:156). The design of P-Record constitutes a good example: the design researchers conducted ethnographic research into existing practices of ICD-care, unraveling the things patients and clinicians had to do in order to make remote monitoring work, such as piecing patient information together from different databases and making time-consuming phone calls (Andersen et al 2011a). From these insights, they gave shape to a tool (P-Record) aimed at supporting this articulation work and thereby improving the cooperation between ICD-patients and the clinicians involved in

their care. However, the relation between cooperation and articulation work is *recursive* (Schmidt & Simone 1996:159): articulation work, itself, and the tools to support it, entail articulation work, so while potentially providing valuable support, P-Record could therefore also be expected to add new complexities to the collaborative work of ICD-care. Baring on preceding STS and CSCW-studies of e-health and telecare, it would be natural to presume instruction work and inclusion work (Oudshoorn 2008) to play a significant role in making P-Record work, along with an extension of the domestication and maintenance work ICD-patients already have to do in relation to the medical devices in their homes. However, during my analysis of use practices, it became apparent that these categories did not capture the work it required for patients to use P-Record, nor did they provide the key to unpacking the discrepancies between patients' and clinicians' perception of what kind of work P-Record was to support and if it succeeded. The articulation work sparked by and conditional for making a participatory scopic device like P-Record work seemed to be of yet another character, one that had to do with the invitation to patients to become *information providers*.

2.2.2 Zooming in on information work

The production and sharing of medical information has been a central topic for CSCW (and medical sociology more broadly), however, most commonly with a focus on this as medical work that is undertaken by professionals (Fitzpatrick & Ellingsen 2012). A key point of reference is Garfinkel's seminal research into clinical record-keeping practices and his underscoring of the social and pragmatic character of these (Garfinkel 1967). Garfinkel shows how what may be 'bad' (inadequate) record keeping from a research or administrative point of view, is a meaningful ('good') practice if the perceived purpose of clinical records is to serve as "*records of therapeutic contracts*" (p.198). When the individual doctor makes an entry, it is in keeping with certain organizational rationales, and based on related anticipations of possible interpretation and uses and shared tacit knowledge; entries can, in Garfinkel's words be understood as "*utterances in a conversation with an unknown audience (...) capable of reading hints*" (p.200). Likewise, readers rely on the same organizational rationale and the (recursive) expectations of the entries' occasional, rather than intrinsic, meaning.

Making Garfinkel's insights relevant to the design of health IT (specifically electronic medical records), Heath & Luff (1996) analyzes the persistent use of paper records despite the availability and promotion of electronic records, showing "*how seemingly individual tasks, such as reading and writing a medical record, rely upon a social and collaborative organization*" (p.355). The paper record affords situational writing and reading of records and the related balancing between acknowledging "defeasibility" – that no matter how precise an utterance is, it will be irrelevant in some contexts – and the reliance on anticipation of others' inference when writing an entry. Doctors "[design their entries] *for a particular class of recipients*" (p.356) and based on tacit knowledge of "*the uses to which the information is regularly put and the knowledge and competencies that suitable qualified colleagues will bring to bear on the text*" (p.357). In a similar vein, Berg & Goorman (1999) point out how medical information is always "*entangled with the context of its production*" (p.53). Doctors shape their entries in for instance medical records according to the purpose of generation and in recognition of "*the evolving array of medical data which continually reshapes their meanings*" (p.55). Recursively, entries are read (interpreted) in light of this circumstance as well as according to credibility of the source. The CSCW-point that these authors are making is, basically, that formalizing these intricate and deeply social processes of writing and reading medical information is problematic. Electronic medical records may not allow flexible and situational production of information (Heath & Luff 1996), or, if intended to also provide information for secondary purposes (for instance management or research), either may be useless or conceal the work that have to be put into disentangling information from the context of production (Berg & Goorman 1999). In other words, formalization through ICT runs the risk of increasing, concealing, or impeding rather than supporting the articulation work involved in the production of medical information by failing to accommodate what Brown & Duguid (2002) also has coined as '*the social life of information*'. As Mort & Smith (2009) put it: "*Information [...] cannot underpin medicine unless it is recognized and defined as generative, dynamic and intimate, rather than storable and deliverable*" (p.215).

While I am inspired by these studies and their basic claims as to the social nature of medical information and the intricate articulation work involved, I have found the concepts offered inadequate to describe the information work involved in the use of P-

Record. This has to do with the inclusion of *patients* as information providers and the script of P-Record as a tool for making information travel from *home to clinic*, which quickly proved to entail the *absence* of a shared organizational rationale or '*interpretation scheme*' (Garfinkel 1967). In using P-Record, patients and clinicians had to draw on other kinds of communicative resources when producing and receiving information, intricately linked to their respective – and very different – understandings of the script of P-Record as an information device. I unfold this analysis and argument in Paper 2; here and in the following section, my aim is to situate and elaborate on the theoretical foundations and contribution of the analysis.

2.2.3 A sociotechnical and dialogic approach to information filtration work

In its design and in clinicians' readings of its script, P-Record can be understood as an information filtration device that is meant to help patients and doctors create a medically relevant problem-definition/story through its structuring set-up (not unlike what Berg (1996) describes as the '*performative function*' of the medical record). This makes it analytically relevant to first of all think of the use practices as information filtration work. In pursuing this conceptualization, I first of all situate my analytics empirically 'close to home', as the term 'filter' commonly denotes information systems that are designed to manage flows of information either automatically (Hanani et al 2001) or by supporting the filtration work of users (Leaver et al 2012), including in telemedicine (Berner & Moss 2005; Eysenbach 2008; Warren et al 1999). Secondly, I draw on a few 'sociologies of filtration', so to speak, to refine the notion of information filtration into a productive analytical concept that is in line with an overall sociotechnical approach. Staying within CSCW-studies of medical work and the use of medical records, we find Berg's (1996) descriptions of how doctors, during encounters with patients, construe a clear story and a manageable problem through a process of channeling and narrowing, distilling and reconstructing information, with the reading and writing in the medical record as a constitutive part of this process. Drawing on ethnomethodology and STS, Berg describes this work of making representations as an "*iterative channeling process*", the outcome of which is a "*highly selective, distanced, abstracted 'representation'*" of the patient (Berg 1996:505). P-Record was exactly thought to assist ICD-clinicians in their 'representation work' – whether during in-clinic

or remote encounters – by delegating part of the ‘iterative channeling process’ to patients and to the system. Since Berg’s analysis focuses on clinicians’ filtration work only, I look to more general accounts of filtration as a social practice in order to inform an understanding of filtration practices that involve patients. Here Kockelman (2013) is a valuable resource, as he develops an anthropology of sieves and sieving. Kockelman describes the dynamic and recursive process of interpretation and adjustment of presumptions that, both, spam filters and humans employ to sort information and produce meaning.

Together, these theoretical resources first of all bring me closer to an analytics that encapsulate the sociotechnical constitution of P-Record as an information filter, which works through the interplay between the filtration device and the filtration work users have to do to make it work as a filter. Secondly, the theoretical resources inform an understanding of this filtration work as a sense-making process based on iterations between expectation (about purpose, use and consequences) and experience, in which the layout of the device can provide more or less assistance. As one of the most striking lessons from the user test of P-Record was the discrepancy between different users’ expectations, my analytics has a final inspiration that allows me to unpack the source and implications of this discrepancy. Drawing on dialogic communication theory (Linell 2001; Phillips 2011) inspired by Bakhtin (1981; 1986), I bring into the equation the notion of “*addressivity*” (Bakhtin 1986:99) to describe the “*other-orientation*” (Linell 2001:35) of patients when shaping information. As the basic analytical figure of dialogic approaches, addressivity expresses the dialogic nature of utterances as always embedded in the structure and imagination of a conversation with an other, whether specific or unspecific, and subsequently shaped through interpretation of preceding utterances and in anticipation of response. Merging this conceptualization of human interaction (and cognition) with *filtration work*, I arrive at an analytics that makes it possible to understand patients’ use practices as guided by what we could call *dialogic* expectations and inference of relevance. Importantly, this conceptualization does not exclude clinicians’ filtration work as users of P-Record – only, as I demonstrate in Paper 2, their dialogic filtration work is guided by different interpretations of the ongoing conversation and their own roles as receivers. They draw on what we could call

different “*communicative projects*” (Linell, 2001:224) – or, what Garfinkel would call “*interpretation schemes*” (1967:205).

In concert, the sociotechnical and dialogic approaches to information and the derived conceptualization of use practices as *dialogic filtration work* facilitate an understanding of the challenges of making use and sense of e-health as scopic arrangements that invite patients to become information providers.

2.3 E-health as participatory projects

So far I have discussed the analytics I employ to: 1) define the e-health system P-Record as a specific kind of sociotechnical arrangement, and 2) unpack the work that goes into making such an arrangement work and, thereby, shed light on the sources of diverging expectations and experiences. This leaves an important dimension of patient-involving e-health untouched, namely how an e-health system like P-Record can be understood as a tool for patient participation – as a *participatory device*. That is, how can the practical manifestations and implications of the overall participatory projects that e-health is embedded in, be brought out? As a participatory device, P-Record can be seen as a rallying point for diverse participatory projects that influence how users perceive and utilize the tool in the specific context of a user test. By engaging with these projects, I stress the broader, more political nature of the communicative projects that guided patients when responding to the invitation to become information providers – to become participants. Theoretically, I do not leave an overall sociotechnical approach. However, I shift from looking at patients’ use practices as responses to an invitation to become information providers, to looking at patients’ use practices as responses to an overall invitation to become participants in both research and care. This is the topic of Paper 3; here in the theoretical chapter, I discuss the literature, normatively as well as descriptively oriented, that has help form a ubiquitous participatory paradigm in healthcare and its relation to e-health design. Subsequently, I introduce an analytics for grasping the practical manifestations and implications of this participatory paradigm in the use of P-Record.

2.3.1 *The participatory turn in healthcare*

A diverse body of literature has been invested in describing and, not least, promoting what has been called ‘a participatory turn in healthcare’ (Prainsack 2011). The notions of ‘participatory medicine’ (Frydman 2010), ‘participatory health’ and ‘the participatory biocitizen’ (Swan 2012) have primarily been used to connote the participatory capacities of new technologies – from online health information to personal genomics. Yet, it also seems a designation suitable to the growing focus on patient participation, more broadly, and in all healthcare-related practices: from care and treatment to research, policy-making, and innovation. Often these practices overlap; yet, scholarly attention has traditionally been foregrounding one or the other. Here, I will sketch the main strands of literature on patient participation, including the position of STS-inspired work. My aim is to show how the multitude of projects that traverse the field, in concert, makes the notion of patient participation highly amorphous and conceptually challenging. I especially find two issues problematic and, thus, calling for a different analytical take: 1) attempts to define and measure participation, and 2) distinctions between participation in different arenas.

Starting with treatment and care practices, patient participation has long been a popular topic in applied healthcare research focusing on patient-professional encounters, such as nursing research and health communication (e.g. Ashworth et al 1992; Cahill 1998; Cegala 2011; Collins et al 2007; Eldh 2006; Roter 1977). The notion of participation is here closely linked to ideals of furthering patient-involvement in medical decision-making and, more broadly, in patient-physician interactions with studies broadly sharing an “*unease with paternalistic philosophy*” (Collins et al 2007:4) and a concern for the “*persistence of asymmetry*” in the clinical encounter (Pilnick & Dingwall 2011:1374, see also Joseph-Williams et al 2014). The consultation is generally perceived as the principle arena for patient participation and, thus, the prime research site. This site is explored through classic interactionist methods, such as conversational analysis, and by drawing on conceptualizations from medical sociology of the divergence between patients’ and professionals’ agendas, competencies, genres, or voices (e.g. Collins et al 2007; Barry et al 2001; Shattell 2004; Heritage & Maynard 2006). The myriad of applied research into patient participation during clinical

encounters can broadly be divided into quantitative and qualitative approaches; however, while these may differ in method, their aim is largely the same: namely, to identify features of patient-clinician encounters that promote or impede participation (Collins et al 2007:15)¹³.

Recently, the programmatic field *Participatory Medicine* has joined this practice-oriented and highly normative interest in patient participation, reviving the past decade's grass root fight for patients' rights and shared decision making (Millenson 2011) while also emphasizing the clinical and organizational benefits of physician-patient partnership (Frydman 2010; Kvedar & Kibbe 2009). With 'partnership' as one of its central concepts, Participatory Medicine taps into a 'collaborative' discourse that invokes the idea of 'patients-as-partners' and 'responsible drivers' more than 'mere passengers' in healthcare (Frydman 2010)¹⁴. Studies in Participatory Medicine revolve around patients' participation in encounters with health professionals, but do not take the encounters themselves to be the prime sites in which participation can be furthered. Rather, Participatory Medicine is interested in the exploration of any activity, structure, or tool that may enable increased patient participation in healthcare (Kvedar & Kibbe 2009). With this broader focus, Participatory Medicine also overlaps with studies focusing on participation and empowerment through patient education (e.g. Bundesmann & Kaplowitz 2011) and social networks (e.g. Guillamón et al 2010) and, importantly in the context of this thesis, holds a strong affinity for e-health (e.g. Gallant et al 2011; Weitzel et al 2009). Increasingly, Participatory Medicine not only focuses on participation in care and treatment, but also promotes the idea of patients-as-partners in the broader practices of healthcare, for instance in service development (McQuillen et al 2013).

STS has also contributed a fair share of accounts of patient participation in care practices, building on classic conceptualizations of medical and patient work (Corbin & Strauss 1985, Garfinkel 1967). While this latter, by now iconic, research initially

¹³ Another distinction can be made between contributions that promote participation for its intrinsic value (e.g. Berwick 2009) and contributions that frame participation as a means to improve safety, patient satisfaction, and clinical outcomes of care, the latter of which seems much more common (Longtin et al 2010; Street et al 2005).

¹⁴ This is a narrative that permeates debates within the field, although with different opinions as to what constitutes a partnership, see website and online journal: www.jopm.org.

focused on making visible how patients manage illness in their everyday lives and unpacking the workings of clinical interactions, it has also informed more explicitly normative approaches. This can be seen, for instance, in the wide use of interactionist methods and concepts in studies of patient-clinician encounters ultimately aimed at furthering participation, as mentioned above¹⁵. STS-studies of patient participation have picked up the heritage from Corbin & Strauss with a more descriptive ambition, namely to unpack patient participation as it is enacted in relation to sociotechnical reconfigurations in healthcare (e.g. Wyatt et al 2010; Langstrup et al 2013; Nielsen & Grøn 2012; Pols 2013; Unruh & Pratt 2008). Rather than to develop and further the practical implementation of a particular participatory agenda, the point of departure for these studies has been to explore different manifestations of involvement and the implications of often explicitly participatory efforts. They have demonstrated how tools that instigate participation are far from the win-win solutions they are envisioned to be: often they entail challenging invisible work for both patients and clinicians and rarely deliver equal partnership (Langstrup et al 2013; Oudshoorn 2008; see also Section 2.2.1). This kind of critique questions the promises of particular participatory projects, but rarely the fundamental value ascribed to patient participation. Like the earlier sociological work it is inspired by, it, thereby, has the potential to feed into more normative projects and contributes to the overall attention to patient participation¹⁶.

The normative engagement of STS is perhaps more vivid in the case of patient participation in policy-making, service development, and research. Here, the STS-informed literature invested in the participatory turn in healthcare runs parallel to the scholarly attention to public participation in other arenas of science, technology, and governance (Irwin 2006; Wynne 2007; Jasanoff 2003; Marres 2012). As a field with a

¹⁵ A more concrete example of how descriptively oriented sociology has fed into ‘the participatory turn’ is the case of the *Stanford Chronic Disease Self-Management Program* (CDSMP), which has gained global popularity as a method for enabling patients to deal with everyday life with a chronic disease (Nielsen & Jensen 2013). The program developed by Lorig and colleagues (e.g. Lorig et al 2000) draws on Corbin & Strauss’s (1985) seminal work on how patients cope with illness, merging this with work on self-efficacy and translating it into an educational program aimed at furthering patients’ self-management (Bury 2010; Nielsen & Jensen 2013).

¹⁶ Henwood et al (2003) have noted another unintended ‘translation’ of STS-insights into the unpredictable nature of patient’s appropriations of e-health into more normative and even deterministic e-health narratives. Specifically, they point to the risk that studies that show the creative use patients make of the internet to build communities risk being interpreted as implying that the internet per se empowers patients.

traditionally strong affinity for democratization, STS has contributed studies of how patients mobilize as political collectives, for instance, through patient organizations, and seek to influence health policies and research priorities (e.g. Brown & Zavestoski 2004; Callon & Raberharisoa 2008; Epstein 2007; Langstrup 2010; Moreira 2011, Rose & Blume 2003) as well as more directly suggested and evaluated methods for involving patients in policy-making and planning (van de Bovenkamp & Zuiderent-Jerak 2013). Part of this STS-literature on patient participation in policy-making, service development, and research, can be characterized as a deeply political project with activist roots – a characteristic it shares with other more applied approaches. Invested in promoting the democratization of patient participation in *research*, we find a wide array of literature exploring and committing to different participatory models, such as *Participatory Research* (Cornwall & Jewkes 1995), *Community-based participatory research* (Minkler & Wallerstein 2010), the *Dialogue Model* (Abma et al 2014), and *Patient-led Research* (Vayena & Tasioulas 2013). Likewise, a large body of literature has been addressing and promoting patient participation in policy-making and service development (e.g. Boaz et al 2014; Facey et al 2010; Pizzo et al 2014; Tierney et al 2014).

Related to the focus on collective modes of patient participation in policy-making, service development, and research, is the focus on how individual patients take part in medical research – a topic that has been extensively featured in a broad range of fields, spanning medical and clinical ethics (e.g. Corrigan & Tutton 2006), organization studies (e.g. Hoeyer 2003), medical anthropology (e.g. Biehl 2007) and STS (Langstrup & Winthereik 2010; Felt et al 2009b). A unifying concern in these otherwise highly diverse fields has been the ethical implications of balancing considerations for care and for research. However, these considerations, or practices, have repeatedly been shown to be highly intertwined (e.g. Fox 1996; Friese 2013; Timmermans 2010), among other things, resulting in the emergence of a more complex picture of patients' motivations for and experiences of taking part in medical research. From this also follows a softening of the otherwise strong normative concern for more active and empowered research participants; instead, the multifaceted relations between patients and professionals (e.g. Easter et al 2006; Wadmann & Hoeyer 2014) and intricate relations

between individual and collective projects in research practices are highlighted (e.g. Felt et al 2009a; Svendsen & Koch 2008).

Linked to e-health, patient participation becomes a truly ubiquitous research topic – traversing an even broader range of academic literature and with an increased blurring of the boundaries between different forms of participation. It, therefore, makes good sense that it is in relation to e-health (in its broadest sense) that the notion of a participatory turn in healthcare has been explicitly used. Using the term '*participatory turn*' in the title of her article from 2011, Prainsack demonstrates how online personal genomics services, such as *23andMe*, employ different models of patient participation. These models allow patients to be anything from consumers picking services off the shelf and passive research participants making their personal data available for genetics to active lay researcher and co-designers of the services offered (Prainsack 2011). Descriptions of such services thus become descriptions of how patients simultaneously participate in interrelated individual and collective projects with no sharp distinction between treatment, research and service development/innovation purposes.

Also, more explicitly normative approaches herald the capacity of e-health (in the sense of consumer-directed as well as healthcare-driven services) for facilitating patient participation in both care *and* in innovation processes. That is, besides inviting and equipping patients to take part in their own care in new ways, e-health is perceived to empower patients to *pursue* more equal partnership with their health professionals and *push* development and implementation of tools for participation (O'Grady & Jadad 2010; Mano 2014). Moreover, through Medical Informatics and other design-oriented fields, the overall participatory turn in healthcare becomes fuelled by user-centered design approaches that seek to involve patients in the design process as informants, test users or even co-designers (e.g. Bate & Robert 2007; Clemensen et al 2007; Eysenbach, 2008; Storni 2013; Unruh & Pratt 2007). User-involvement may be regarded as anything from merely an instrument to build knowledge of users and practices, to a democratic project of delegating initiative and control over innovation processes to users. The latter paradigm was originally promoted by Participatory Design (PD) (e.g. Kensing & Blomberg 1998; Kensing 2003; Schuler & Namioka 2013). However, as Kensing & Greenbaum (2012) have pointed out, PD has more often only lent particular

techniques to design projects than it has actually been practiced in its ‘pure’ form – with the CITH-project and development of P-Record being no exception. Nevertheless, the political connotations of PD are also to be found in other user-centered approaches and, thus, seem to feed into the overall participatory project of e-health (e.g. Brennan et al 2010; Das & Svanæs 2012).

2.3.2 Participatory projects in practice: strategies, devices and tactics

In concert, I believe that the extensive and diverse literature on patient participation justifies the notion of a participatory turn – in healthcare practices and policies, but certainly also in academic literature. However, as I mentioned in the introductory remarks, the heterogeneous literature on patient participation also contains two major conceptual challenges, with implications for how we can approach participation as empirical phenomenon.

Firstly, the term participation often remains undefined (Collins et al 2007) and is used interchangeably with other terms such as involvement, engagement and empowerment (Menichetti et al 2014), making what is being studied and/or promoted, unclear. This conceptual vagueness has repeatedly been noted as a big challenge (Barello et al 2014; Cornwall & Jewkes, 1995; Gallivan et al 2012; Kvedar & Kibbe, 2009; Smith 2014) and both empirical and theoretical efforts have been used on conceptual clarification (Cahill 1998; Corrigan & Tutton 2006; Eldh et al 2010; Thompson 2007). In explicitly normative and applied strands of research, this has resulted in the establishment of criteria and measurements for patient participation (Eyssen et al 2011; McQuillen et al 2013; Phillips et al 2014). A popular reference for efforts to define and establish measurements is the classic text by Arnstein (1969), introducing a typology for citizen participation arranged through the notion of a “*ladder of participation*” with “*each rung on the ladder corresponding to the extent of citizens’ power in determining the plan and/or program*” (p.216). Arnstein’s conceptualization of participation can be described as a hierarchy of the different degrees of influence serving to criticize what she calls “*empty ritual(s) of participation*” as opposed to “*having the real power needed to affect the outcome of the process*” (Arnstein 1969:216). While this conceptualization may be instrumental in bringing forth discrepancies between democratic ideals and practical realities of participatory efforts, I also find it

problematic, as it may lead to a reductionist understanding of what ‘real participation’ is, disregarding or even dismissing the manifold and sometimes subtle ways in which citizens – or patients – shape their engagement.

Secondly, subcategories are used to distinguish between different forms of participation that may not hold up in practice. One such distinction is between so-called ‘individual’ and ‘collective’ participation – or, as it is also conceptualized, between ‘private’ and ‘public’ or ‘patient’ and ‘citizen’ participation (Florin & Dixon 2004; Williamson 2014). This distinction seems to largely correspond with another distinction, namely between different arenas of participation: care/treatment, policy-making and service development/innovation, with private participation linking to care/treatment and public participation linking to policy-making and service development/innovation. Participation in research is explored as both private and public forms. However, as the literature on, for instance, patient participation in clinical research has demonstrated (e.g. Timmermans 2010; Wadmann & Hoeyer 2014, see the previous section), these distinctions may not describe actual participatory practices very well.

These two conceptual challenges – how to define participation and the practical overlaps between arenas and forms of participation – along with the particularly pervasive participatory project of e-health, have made me look for another way around the phenomenon of participation. That is, I have sought out an analytics that could help unpack the workings of P-Record as a tool for participation, taking its entanglement with a research project into account and focusing on an ontological question of *what participation is* without moving on to ask (how) *can we recommend it* and (how) *can we measure it*, as otherwise common in the literature (e.g. Collins et al 2007; Eldh et al 2014; Florin et al 2006).

I follow in line with STS-scholars who have called for a more critical look at the participatory project – in healthcare and other fields. In a commentary, Prainsack (2014) argues that it is time to take a look at the distribution of power and agency in participatory medicine in order to move towards “*genuine participatory medicine*” (p.1). Prainsack calls for attention to three issues. Firstly, she criticizes the tendency in the emergent field of participatory medicine to make participation rest on encouragement or acceptance from professionals. Rather, scholars should be sensitive to

the many forms in which participation comes. Secondly, Prainsack stresses the importance of acknowledging the role of infrastructure for participation as *“people’s freedoms are inevitably limited by the means and resources available to them”* (p.1). Thirdly, Prainsack underscores a possible flipside to participatory efforts: the risk that the opportunity for participation becomes a duty (p.1). In a similar vein, Felt et al (2009b) have called for a critical approach to the participatory turn in healthcare and succinctly pointed out the paradox of public discourse about patient participation: that citizen-patients are supposed to enact a kind of *“disciplined engagement and participation”* (p.37). In this discourse, the invitation to participate is not open; rather, choice is actually narrowed down by the expectations of participation as conditioned by the education of citizen-patients towards a particular kind of rationality (p.39). But in contrast to Prainsack, Felt et al do not start from a notion of ‘genuine participation’. Their aim is more exploratory, and so is their subsequent call for a combination of inquiries into the *“pervasive conceptualizations”* of ‘participatory e-patients’ and *“in-depth studies of social practices in these changing health contexts”* in order to get a *“better understanding of the process of co-production of both techno-scientific innovations and societal change in the e-health domain”* (p.39). I follow in line with Felt et al in this exploratory approach: while I agree with Prainsack’s call for attention to the multivalency and power relations of participation, I do not find it useful to start in an inquiry into participation with a definition of what constitutes ‘genuine participation’. Rather, I wish to go more empirically about the phenomenon of participation and explore how patients in different ways participate within the invitation and (infra)structure available at a certain moment: how do patients make use of the available ‘space of agency’?

Here, I find it useful to put in a distinction between invited and uninvited participation (Wehling 2012). Where participation through activist groups and organizations or online consumer-directed services, such as personal genomics, can be regarded as *uninvited* participation, ‘healthcare-driven’ e-health, like P-Record, *invites* patients to participate in new ways. These two forms may, of course, also overlap: uninvited participation may be welcomed and gradually integrated into care practices, and invited participation may entail participatory practices that are regarded as problematic overflows. Nevertheless, the distinction is important in that it directs attention to the

different offsets for participation and, correspondingly, the specific implications that relate to these. P-Record, the e-health system that I study, invites patients to participate. This leads me to another STS-inspired call for practice-oriented studies of participation as projects. In her study of participation in environmental matters, Marres (2012) points to two tendencies that I also find highly relevant for e-health and patient participation. Firstly, participation is increasingly deliberately sought furthered in material forms: Marres notes how *“a wide range of initiatives aimed at fostering public participation are explicitly designed to locate participation in material practices”* (p. 2). This way objects and technologies come to mediate certain participatory projects in the way that they pose an invitation to participate. As participatory device, P-Record can thus be said to materialize an invitation to participate and facilitate participation through use practices. Secondly, with participation deliberately located in material objects, the role of STS in studying ‘material participation’ changes slightly. STS has long been attuned to the role of objects and technical arrangements in social practices (Latour, 1992; Akrich 1992), including participation and here with some inspiration from American pragmatism and classic work on public participation (e.g. Dewey 1991 (1927); see Marres 2012). However, the role of STS is no longer to make visible the otherwise overlooked role of objects. Rather, it is to *“note the normative variations among enactments of material participation”* (Marres 2012:2). Following Marres, I set out to unpack the ways in which users, and patients in particular, react to the participatory projects inscribed in P-Record in the specific use contexts, that is, how they *enact* participation through a technology that is invested with diverse participatory projects.

To explore enactments of participation, I specifically draw on de Certeau (1984) and his conceptualizations of how people as users, or consumers, engage with everyday objects and technologies, which are inscribed with specific normative expectations. De Certeau conceptualize use practices as *tactics*, defining tactics as the creative ‘*making-do*’ with arrangements that are given to users – be it television programs, kitchen devices, urban infrastructure, or e-health (de Certeau 1984:29-30). De Certeau’s point is that users are neither just passively consuming nor do they enjoy unlimited freedom in their use practices. To once again paraphrase Prainsack (2014), users’ are always faced with a delimited ‘space of agency’, yet there is, nonetheless, a room for users to *“reappropriate the space organized by techniques of sociocultural production”* (de

Certeau 1984:xiv). De Certeau departs from a criticism of the structural power of consumerism and capitalism, and he draws out users' tactics as inherently a kind of opposition to the *strategies* imposed on them by elites, producers, and decision-makers (p.35-36). It is due to this orientation towards structural power and strategy that I find de Certeau's approach fruitful, but, at the same time, also problematic. I find the notion of tactics a useful way of denoting material enactments of participation through e-health because it captures the relation between creative use practices and the larger political structures – or projects – embedded in technology. The notion of tactics thus serves to highlight the both restricted room for enacting participation by invitation *and* the unpredictability of what an invitation sparks – what it produces. However, the case of e-health challenges de Certeau's clear distinction between tactics and strategies with the former standing in opposition to the strategies of production by representing a way of “*produc(ing) without capitalizing*” (p.xx). Following Marres, the material inscription of an invitation to participate may be understood as a result of a capitalization on patients' tactics. That is, with the participatory turn in healthcare, participation has become a strategy – a political¹⁷ and commercial project that finds its way back to the users through participatory devices like e-health. Thus, the relation between tactics and strategies, here, seems to constitute more of a loop than a linear power relation.

I suggest, that with this important moderation, de Certeau's conceptualization of use practices as tactics is very suitable for unpacking the role of diverse participatory projects in e-health use – projects that, through their ubiquity, makes patient participation through e-health difficult to categorize as private or public, or belonging to a specific arena. As Marres has also noted in relation to devices for instigating participation in environmental issues, everyday technology use may, indeed, be a form of political engagement.

With this outline of the literature and my own analytical take on (patient) participation, I complete my presentation of the theoretical framework of the thesis. In Chapter 4, I discuss how the three parts of my analytics (*arrangements*, *work*, and *participatory*

¹⁷ In Denmark, as in many other countries, there has been a noticeable political uptake of the broad practice-oriented scholarly attention to patient participation, with patient participation being a frequent topic in health policies and guidelines (e.g. Regeringen 2013; Sundhedsstyrelsen et al 2012; KMD 2014; European Commission 2012).

projects) supplement each other and, in concert, allow for an analytical progression through my research questions and towards an overall ethnography of e-health, when applied in the different papers. Meanwhile, in the next chapter, I turn to the methodological framework of the thesis and the empirical work that the four papers are based on.

3. Methods: exploring through intervening

Empirically, the thesis builds on ethnographic fieldwork, but with a particular interventionist dimension: by acting as the facilitator of the user test of P-Record, I have been directly engaged in a central part of the practices studied. In this chapter, I present and discuss my empirical work with special attention paid to the benefits and challenges of this close engagement with the field. I seek not only to add transparency and reflexivity to the research presented in the thesis, but also to, by example, contribute to a broader methodological discussion of how social scientists can respond to invitations to take part in innovation projects.

The chapter is structured roughly according to chronology. I start by sketching the occasion and framework for my research project and how I have sought to turn a specific invitation into an ethnographic opportunity, drawing on STS literature on ethnographic engagement and intervention. I then describe my empirical work, which consists of two parts: a user test of P-Record and additional fieldwork. The two parts are closely linked and ultimately amount to one ethnography of e-health and patient participation in heart care, but the methodological premises and implications of each differ substantially. I end by discussing my analytical process and dissemination of results, and how this links to doing research by invitation.

The methods chapter can be read, overall, as an account of my situated research *tactics* that were sparked, but not determined by, an invitation to do innovation-oriented research on e-health and only gradually took the shape of a participatory research *strategy*. It is an account of which research project(s) I participated in; how I facilitated and studied local participatory practices; and, how I, at the end of the day, fed into the larger participatory project of e-health. The aim of my methodological considerations is not programmatic; yet, I believe that I provide a valuable example of how one may turn challenging research conditions into productive occasions for exploring emerging technologies and practices, and intervening in the projects that surround these technologies and practices.

3.1 Research by invitation

I entered the CITH-project as the only social science researcher among a group of design researchers who were committed to a hands-on methodological approach informed by Participatory Design (PD) (Kensing & Blomberg 1998) and action research (Checkland & Holwell 1998), and intrigued by the prospect of exploring the methodological possibilities of highly performative engagement with the field. I also expected to find a position from which I could remain somewhat distanced and participate without actually initiating the experiments that were to take place and, thereby, still be on somewhat familiar ground as an ethnographer engaging with practices that are ‘already there’. However, due to the methods and organization of the project, this position did not exist; as the research leader pointed out at one of our first meetings: if I wanted to study the use of P-Record, I would have to create it, that is, I would have to facilitate the user test. The user test became a precondition for as well as an opportunity to ethnographically inquire into e-health practices. This order of events and reasoning is important, as the relation between conducting a user test and producing ethnographic knowledge has stayed in line with this order throughout my research process. Contrary to how ethnography is often made into a tool for design and evaluation of ICT (Blomberg & Karasti 2013), the user test, largely, became a tool for my ethnographic ambition. I put in the modifier ‘largely’ for two reasons: firstly, because the user test also became something more than an ethnographic tool, namely an instigation of participation with potential practical consequences, and secondly, because the ethnographic insights also, ultimately, were translated back into recommendations for design (in Paper 4). I will elaborate on this shading of the ‘aim-tool relation’ between ethnography and user test throughout the methods chapter.

For now, I will first present the project that I was invited into. I then situate my considerations regarding this invitation within discussions about intervention in STS. In particular, I tap into recent discussions about the role STS researchers can play when directly invited to participate in innovation processes and, moreover, when “*specifically invited to be the ones who invite users*” (Jensen 2012:30). Subsequently, I outline the specific interventionist approach I arrived at, embracing the facilitator role and embarking on conducting the user test as an ethnographic experiment.

3.1.1 The CITH-project and the development of P-Record

So far, I have only made general references to the prime empirical occasion for this thesis: the development of P-Record through the innovation project, CITH. In Section 1.2., I sketched the organization of remote monitoring in ICD-care and the Danish e-health agenda which in concert formed the outset for the project. The CITH-project was initiated in 2008, as a collaborative research and innovation project that brought together design researchers, clinicians, and social scientists. In the last phase, when prototypes had to be translated into a fully technically implemented application, a private company joined the project, as conditioned by the public funding agency. Initially, the project partners set out to *“to analyze existing collaborative practices amongst heterogeneous actors who manage ICD patients, with the aim of designing, developing, and evaluating IT applications and services supporting the work of both healthcare professionals and patients”* (Andersen et al 2009:1) in order to reach an overall goal of *“improving the quality of life of patients and increase the quality and efficiency of treatment and care plans”*¹⁸. The project thus tapped right into a public e-health agenda by stressing the potential of ICT to improve quality as well as efficiency of care (NSI & Sundhedsstyrelsen 2012). What set the CITH-project apart from this agenda and other e-health projects was that technological innovation, here, constituted both solution and problem. Part of the design ambition was to reconfigure the telemedical service by adding an extra layer and thereby potentially counter some of the implications of remote monitoring (as mentioned in Section 1.2).

As pointed to in the previous chapters, the CITH-project also tapped into a broader participatory paradigm in healthcare, which was merged with the participatory design methodology of the project. In the first three years of the project, design researchers worked together with clinicians and patients to give shape to prototypes through iterations of exploration, design activities, and interventions (Andersen et al 2011b; see also Paper 4). One group of researchers focused on supporting coordination between clinicians, primarily informed by CSCW (Mønsted 2012), while another group experimented with designing patient-oriented features (Andersen et al 2011a+b). Together, the two groups arrived at a requirement specification which was subsequently implemented by a software company. This part of the process was far from seamless,

¹⁸ Quote from the CITH project application, 2007 (confidential document).

with contractual disputes and diverging cultures and expectations clashing in the collaboration between researchers, clinicians, and private partners. This ultimately manifested in a prolonged process and an insufficient translation of requirements into a working system, which failed to match the technological and organizational complexity of ICD-care.

I joined the CITH-project as a doctoral student during this last phase. Therefore, I was not part of exploration and design, but instead part of preparing and executing the *test and evaluation* of the application. During this process, the test's scale and purposes were gradually changed from a *large-scale* pilot implementation, involving partial reorganization of ICD-care and design adjustments followed by clinical testing and, ultimately, put into daily use, to a *small-scale* user test, aimed at generating insights for future e-health-related research and design. This reduction of scale and ambition had several causes that, not all clearly tangible, in concert reveal the intricacies of multidisciplinary and cross-sectorial innovation projects as well as the difficulties in making e-health attractive solutions when visions meet the practical realities of healthcare. However, while the course of events in the CITH-project certainly would have been interesting to inquire deeper into, I was only in a position to gain fragmented insights. For one, the project did not succeed in obtaining funding for the clinical test that should have followed the pilot implementation. This was a demotivating factor, especially for the participating clinicians whose research interests were primarily vested in the clinical test. At the same time, delivery of a test application that functioned well enough for pilot implementation was repeatedly postponed. This caused growing concerns among the researchers and clinicians about the viability of the collaboration with the private partner and ultimately pushed the schedule to a point where a pilot implementation would no longer be possible within the project timeframe. As a result it was decided to settle for a small-scale user test.

As a project participant and one of two doctoral students who, in practice, would have to execute the test activities, I was part of the negotiations that ultimately led to this decision – a decision that served to satisfy all project partners' needs for some sort of evaluative outcome, including my need for empirical material. Yet, when the other doctoral student opted out, I had to rethink the invitation to do interventionist research:

seizing the chance of producing empirical material also meant being the sole facilitator of the user test. There was certainly no familiar, distanced research position available anymore, if there ever was, nor was there a clear collective goal for the user test. The latter meant that my ethnographic and STS-informed research interests could take center stage, with expectations of design-relevance pushed to the rear. In concert, the user test posed an open and at the same time disturbingly incalculable invitation to do intervention.

3.1.2 STS and intervention

The question of how STS researchers are or should be intervening in the fields they study has been extensively discussed within STS (for summaries of these discussions, see Jensen 2012; Zuiderent-Jerak & Jensen 2007; Zuiderent-Jerak 2010). For some time, the discussion revolved around the critique that STS studies did not make contributions of practical relevance for the scientists who opened their laboratories or proactively engaged in larger issues related to technological change. The critique came with the normative claim that STS researchers should, to a larger degree, intervene in the local practices they study, as well as in society at large, on the basis of the ethnographic insights and concepts they produce. The call for intervention was, thus, first of all part of advocacy for an activist approach to STS that focused on “*how knowledge and technology [...] might be better constructed*” (Hess 2001:240) and with intervention linked to political engagement (Martin 1996) or even “*leadership*” (Hess 2011:242), prescriptive contributions (Timmermans & Berg 2003), and dialogue (Hasu & Miettinen 2006). Secondly, the normative call for intervention in STS was based on methodological arguments, claiming the epistemological value of doing intervention. For instance, intervention was seen as a way of overcoming the strict division between research subject and object (Hasu & Miettinen 2006) or, echoing classic experimental approaches in sociology (e.g. Garfinkel 1967), as a way to gain understanding while effecting change (Martin 1996).

Whether based on political or methodological arguments, the normative call for intervention in STS has been criticized for resting on a wrong premise, namely, the perceived *lack* of intervention (e.g. Danholt 2008; Jensen 2007). In line with a perception of science and knowledge production as performative and relational rather

than representational and objective, a prevalent claim in STS is that knowledge always intervenes in the world. It does so through the constitutive propositions it puts forward about the world. As any other social practice, any other form of description, science, thereby, has ‘world-making effects’. Correspondingly, any ethnography is a direct intervention into the field of study. First of all, the field and the object of our studies are never just ‘out there’ for us to enter – they have to, and inevitably will be, co-constructed through engagement and negotiation, as demonstrated by for instance Winthereik, Berg & de Bont (2002) in their account of the substantial work, but also analytical productiveness, of negotiating access in a study of ICT in primary care. Secondly, as we move around in the field, ask questions, break routines, and introduce new concerns, we influence – or *affect* (Despret 2004) – the practices we study, that is, we *intervene*. Affection is not to be understood as contamination or bias. With a relational and pragmatic epistemology, any objectivist ideals are done away with (Danholt 2008). Rather, the premise of knowledge production is exactly *productivity*: through our engagement with and representations of the practices we study, we simultaneously shape them (Langstrup & Winthereik 2010; Vikkelsø 2007). Therefore, it makes little sense to discuss intervention in STS as norm or choice. Ethnographic inquiry – and thereby STS – is ‘interventionist by nature’ (Zuiderent 2002; Jensen 2012), just as *any* description of the world is never just a representation, but also an intervention.

However, it is still relevant to discuss *how* STS researchers can and should intervene in different ways, not least when invited to, as it is increasingly the case (Jensen 2012). This is also a question of how to respond to particular ideas of and requests for ‘practically relevant’ contributions that can help ‘solve problems’ (Zuiderent-Jerak & Jensen 2007). How can “*STS researchers creatively use bits and pieces of their STS background, methods and experiences to create activities that feed into their collaborations with others*” (Jensen 2012:29)? Or, approaching the challenge the other way around: how can we convince those we collaborate with that “*what constitutes an intervention and a contribution can come in many forms*” (Danholt 2008:44)? In a study of STS researchers’ participation in Danish user-driven innovation projects, Jensen (2012) describes what he calls ‘intervention-as-composition’ (referring to Latour 2010), that is, intervention where the STS researcher acts as a mediator bringing together

previously unconnected actors – for instance a company and potential users/customers. In the case of user studies, this type of intervention often also includes “*getting users to do certain things, while making decision-makers recognize these things as being innovative*” (p.30) – what Jensen also terms ‘middle management’ and calls for scholarly attention to, since STS researchers increasingly find themselves in this role. Based on his own experiences of participating in the development of a hemophilia care center, Zuiderent-Jerak (2010) encourages STS researchers even more directly to “*engage themselves*” with for instance “*the proactive construction of healthcare services*” (p.679). With the notion of ‘situated intervention’, Zuiderent-Jerak advocates an interventionist attitude in STS that allows for a deliberately normative engagement and orientation towards instigating change, but without departing from predefined social problems. In formulating this third way, Zuiderent-Jerak refers to Martin (1996) and his conceptualization of intervention as “*dealing with the interplay of developing an understanding of a field while at the same time trying to change it*” (Zuiderent-Jerak 2010:683-4). With these contributions, the discussion of intervention in STS arrives at pragmatic stance that seemingly bridges the call for more activist STS and the defense of ‘description’ as always already interventionist. Subsequently, this pragmatic stance diverts the discussion towards the question of *how and with which effects STS can welcome different kinds of invitations to intervene*.

3.1.3 From condition to opportunity: the user test as an ethnographic experiment

The pragmatic, situated approach, which seems capable of uniting the different perspectives on intervention in STS, has inspired me to reframe the invitation to conduct a user test of P-Record from troublesome condition to “*fruitfully risky business*” (Zuiderent-Jerak 2010:678), that is, to an ethnographic opportunity. I seized this opportunity without critical methodological hesitations to its interventionist nature per se, since *any kind of* ethnographic inquiry would be an intervention, and encouraged by the prospect of the heuristic as well as normative benefits of doing what Jensen (2012) calls ‘middle management’. The bracketing of the initially prevalent design and evaluation aims in the CITH-project meant that I could focus on appropriating the user test to my ethnographic interest in how e-health invites patients to participate as information providers, the work it entails, and the participatory projects involved. Thus,

from the outset, my main concern was with how to make sense of the user test and the practices unfolding there as an ethnographic site while intervening as a facilitator.

I conceptualize the user test as an *ethnographic experiment*¹⁹. With the term ‘experiment’, I wish to underscore the particularities of my role as *facilitator* and not just observing participant, thereby also marking the difference between the kind of intervention I have undertaken and interventions as they are commonly done in STS. Although Jensen’s term ‘intervention-as-composition’ likewise would apply and has the advantage of also encapsulating the final contribution of one’s intervention, I find the notion of ethnographic experiment more descriptive of my *process* of conducting the user test. In conceptualizing the user test as an ethnographic experiment, I draw on two different approaches to combining design research with STS in the context of designing for chronic care (Danholt 2008) (Andersen 2012; Moll 2012).

In his study of diabetes, Danholt (2008) introduces a self-management device to a group of patients. His purpose is not to evaluate the device as ‘a solution to the problem of diabetes’, but to inquire into *what diabetes is*. Danholt draws on scholars such as Stengers (2005), Despret (2004), Strathern (1991) and Latour (2005) to lay the epistemological grounds for the experiment as a knowledge instrument. The basis is an anti-essentialist, relational onto-epistemological position (as also sketched above) entailing the view that any given phenomenon – whether an animal’s behavior, a disease; a care practice; or an e-health system – is constituted through relations, rather than being something in and by itself. From this relational ontology follows the epistemological claim that not only do we always influence what we study, but our study objects also come into a particular being through our engagement with them. Subsequently, the task for a researcher is to consider *how* to engage with the object of study in a way that allows for something *interesting* to emerge. How can we “*enlarge the capacities*” (p. 79) of, for instance, diabetes or ICD-care to become something else? We can, for instance, do this by experimenting with a self-management device for

¹⁹ The term ‘ethnographic experiment’ is used widely and for different kinds of ethnographic engagements. For instance, Mann et al (2011) use the term to describe their exploration of eating and ‘tasting’ with their fingers and, thus, as a term to describe a sort of collective auto-ethnographical study. Another, and quite different, example is Watson (1996) who describes the ‘ethnographic experiment’ as an anthropological method for studying and theorizing learning processes through staging particular learning situations – within management education, in the specific case.

diabetes patients – or an e-health system for ICD-patients – and thereby “*provide opportunity*” for the specific disease, care practices, and device to be enacted (p.83). Danholt frames the components of his experiment (the self-management device; the theoretical concepts; his research interest etc.) as “*post-human devices*” for studying diabetes (p.75). These are “*like instruments in a laboratory*”, that is, “*they are the means that enable the object of study to be elicited in specific ways*” (p.75). In formulating this STS-inspired, ‘post-human’ approach to design and intervention, Danholt turns the prevalent methodology in design research upside-down: rather than perceiving of and evaluating the specific self-management device as a solution to the pre-existing problem of diabetes, he uses the device to enable the alleged problem of diabetes to become something else and, importantly, to provide the users the opportunity for *resisting* the problem-solution narrative of the device.

Danholt’s approach is based on a critique of design research and its focus on ‘solutions’, and, by and large, brackets any design ambition and instead commits to enacting and understanding the ‘problem’. In contrast, Andersen and Moll stick to a design agenda (Andersen 2012; Moll 2012; Andersen et al 2011b) in their work on design in ICD-care²⁰. However, they do so with the same critical stance as Danholt towards design methodologies that take users and problems to be ‘out there’ prior to the design and implementation of ‘solutions’. Instead, they propose a practice of ‘collectively prototyping’ with users and conducting design interventions as a way to bring ethnography and design together in experiments with (future) practices and relations in ICD-care. This is also an answer to a call in CSCW for *integration* rather than translation or *bridging* between ethnography and design (Blomberg & Karasti 2013; Andersen 2012:14). Andersen and Moll draw inspiration from a multitude of fields: Participatory Design (Bødker, Kensing & Simonsen 2004; Suchman, Trigg & Blomberg 2002), action research (Checkland & Holwell 1998), design anthropology (Halse 2008), and not least STS (Latour & Woolgar 1986; Law 2004; Mol 2008) to formulate their ‘hybrid’ research agenda focusing on *design interventions*. They summarize this as: “*a strategy of multiple becomings, wherein assemblages of patients, health professionals,*

²⁰ Tariq Andersen and Jonas Moll both conducted their doctoral research, to which I here refer, as part of the CITH-project. Thus, the design and research activities that I here summarize produced the prototypes that later were translated into P-Record.

diseases, information technology, prototypes, and design researchers together perform shifts between promoting new practical design solutions and raising novel questions on the socio-material complexities of healthcare” (Andersen et al 2011b:1). Thus and ultimately, what they believe their design interventions to enable is the constructive exploration of what ICD-care *may become* through new ways of involving patients. Importantly, Andersen and Moll underscore the constructive part of their agenda: they wish to “*explore configurations of future heterogeneous ensembles in an effort to move closer to a desirable collective of patient 2.0.*” (Moll 2012:63, my emphasis).

My approach to the user test of P-Record as an ethnographic experiment combines the two approaches sketched above, without actually reconciling them. As both Danholt’s diabetes self-management tool and Andersen and Moll’s prototypes, P-Record and the user test became a tool to explore through disrupting (as did Garfinkel in his ‘breaching experiments’ (1967)), and to study the *becoming* of use practices and, not least, the work that goes into this first-hand. The user-test of P-Record became a *heuristic device* for doing ethnography of emerging as well as existing practices in ICD-care rather than a tool for evaluating e-health as a specific kind of solution²¹. Like Danholt, I did not conduct the experiment *in order to construct*, but instead to provide patients and clinicians the opportunity to *enact a potential future* and, importantly, to *resist* the (future) practices and roles inscribed in P-Record and thereby ‘teach us’ more about what e-health and patient participation may entail. Giving supremacy to this ethnographic ambition and bracket design was also a way to avoid bringing “*certain assumptions regarding the desired changes*” with me, as otherwise almost unavoidable when doing design research (Pors et al 2002:3). To engage in the constructive design of e-health came second and, ultimately so, in a rather indirect manner by suggesting a framework for designing e-health rather than actually engaging in design or formulating requirement specifications (Paper 4).

By treating the user test as an ethnographic experiment, I have – like Danholt and, to some extent, Andersen and Moll – turned the typical relation between intervention and ethnography in much user-centered design research ‘upside-down’. Rather than instrumentalizing ethnography for design, I have made a specific design object and

²¹ I elaborate on *how* the user-test functioned as a heuristic device in Section 3.2.3.

evaluative activity an instrument for ethnography. The broader field of IS and user-centered design has been criticized for taking a representationalist approach to ethnography (Suchman 1995; Danholt 2008, Blomberg & Karasti 2013), that is, for treating ethnography as an instrument for ‘getting close to’ and depicting the *reality* of users and their perspectives. This utilization of ethnography has been pointed out as problematic in that using ethnography as a tool for representation implies reducing complexities and impedes the critical potential of ethnography (Danholt 2008: 53)²². In a similarly vein, others point to what they believe to be a ‘misappropriation of ethnography’ in design: that is, the conduct of fieldwork in order to produce requirement specifications rather than analytically interesting understandings and concepts (Anderson 1994; Button 2000; see also Blomberg & Karasti 2013). While I agree with this critique of common approaches to ethnography in the broader field of IS and user-centered design, including in design of e-health, I will not go further into nor seek to contribute to the discussion of how ethnography may or may not be utilized for design. My main preoccupation in this thesis is *not* with arguing for a critical-ethnographic, STS approach to design. Rather, I explore and argue for the *ethnographic value* of doing (design) interventions. This means that I primarily seek to make a methodological contribution to STS and to the more analytically oriented part of CSCW. Only to a lesser degree has my intervention ultimately also led to contributions that, in different ways, can be perceived as *analytically* and *practically* relevant for more design-oriented fields, including directly design-oriented CSCW. I elaborate on this in Chapter 4.

Ultimately, what I hope to demonstrate in this thesis is how an ethnographic experiment like the user test of P-Record may enable us to *understand* as well as, down the line, *inform the design of* emerging technologies, such as e-health. Not surprisingly, conducting an ethnographic experiment continuously involves methodological, ethical, and not least practical challenges. However, these challenges can also be seen as contributing great heuristic potential to the user test, as I describe in the next section,

²² Importantly, PD stands out among other user-centered approaches in that it does not pursue ethnographic accounts as representations of reality but rather seek to involve users directly in the design process.

where I outline the user test and discuss its productiveness as an ethnographic experiment with e-health and participation.

3.2 The user test of P-Record

In this section, I present the user test of P-Record, starting with a description of the test application and the process, and ending with a discussion of the heuristic benefits and challenges of the user test as an ethnographic experiment with e-health in heart care.

3.2.1 *Presentation of P-Record*

P-Record was designed as a web application accessible through a personal login for ICD-patients, clinicians and, during the user test, me as facilitator. Once logged on, patients were met by a user interface consisting of the following features, designed as ‘widgets’: Calendar, Preparation, Medication, Logbook, Messages, and Network (see appendix III for screen shots of the user interface for each of the features). In the *calendar*, patients could create a list of scheduled appointments for in-clinic ICD follow-up, remote ICD follow-up, and consultation at the local hospital. For each appointment a *preparation* form needed to be filled out. The form was generic for all types of appointments, consisting of what was basically a four-part electronic questionnaire, designed to gradually narrow down patients’ accounts from free text descriptions of general well-being to predefined symptom categories and questions for the upcoming appointment. As part of the preparation form, patients were reminded to update their *medication* list. The medication feature consisted of forms to be filled out by patients for all prescribed and over-the-counter drugs they were currently taking with information about type, indication, prescribing physician, starting date, daily intake, and any side-effects experienced. While the preparation and medication features were clearly shaped as tools to provide clinicians with information, the *logbook* was primarily designed as patients’ own tool. In the logbook patients could create three types of notes in a free text format: symptoms note, illness trajectory, and diary note. The *network* feature was a patient-to-patient feature with the possibility of granting other patient users access to the logbook and of getting in touch using the application’s internal *message* feature. The message feature also allowed two-way communication between patients and clinicians. However, responsibility issues regarding email communication

from patients to clinicians remain unsolved, resulting in a disabling of this use of the feature.

Clinicians' user interface was almost identical with that of patients, showing the entries of selected patients in the widget format, only without the network feature and with the addition of a *summary* feature. Materializing the design ambition to support clinicians' collaborative work in a field of high technical specialization and distributed sources of information, the clinical summary displayed formalized, clinical patient information relevant for ICD and cardiovascular care accessible for clinicians at both the device clinic and the local hospital. Requiring no active involvement of patients, this part of P-Record has received marginal attention in my research.

3.2.2 The process: timeline, activities and participants

Applying the term 'user test', I stick to the shared language in the CITH-project, which builds on an information systems terminology. However, as I have treated it as an ethnographic experiment into e-health and patient participation, I have *not* conducted the user test according to a protocol intended to be in keeping with examples and norms in information systems design. Rather, the user test was shaped according to opportunity (what was possible) and evolving ethnographic insights and questions (what gradually emerged as rich empirical situations to pursue). Opportunity was especially defining for the timeframe. The user test took place over the course of three months in the winter 2012/2013. As mentioned in the previous section, this short timeframe was a result of a delay in the technical implementation process and a fixed overall timeframe of the project; a longer timeframe had been desirable to allow for users to become more familiar with P-Record and for routines to start forming. However, the three-month timeframe did allow for a critical spectrum of activities to take place showing interesting variations as well as overall tendencies in use practices that ultimately proved to constitute rich empirical material for exploring my research questions.

The timeframe was also one of the few inclusion criteria in the recruitment of patients: the participating patients would have to be able and willing to have existing appointments rescheduled to take place within the three months and further to take part in instruction and interview activities. Geography was another criterion, as the user test could only accommodate ICD-patients living in the participating local hospital's district. Finally,

basic IT skills and equipment were required. Patients were contacted by telephone, presented to the project and, upon expressing interest, given further information by mail before signing up and making appointments. The majority of the patients that were contacted expressed interest in participating in the project, and, after the positive response of 10 patients, recruitment was stopped. Out of these 10 patients, three declined participation after receiving written information and one opted out before the first visit due to a sudden worsening of her medical condition. The remaining six patients participated throughout the three months, yet with very different engagements as I show in Papers 2 and 3. During these three months, the patients took part in the following activities, with a few exceptions due to logistics: a first instructional visit in their homes, a remote ICD follow-up, an in-clinic follow-up, a consultation at the local heart clinic, and a final interview in their homes. In between these encounters, the patients had to use P-Record to prepare for the upcoming appointments with the clinics, filling out the preparation form, creating a medication list, and otherwise use the different features of the system depending on interest.

Besides the six patients, five clinicians took actively part in the user test: two cardiologists and one technician at the device clinic (another technician participated for a month, but then opted out due to illness) and two cardiologists at the local hospital's outpatient heart clinic. The cardiologists had all been involved in the CITH-project from the outset, participating in design and research activities that led to the development of P-Record. This gave them a certain stake in the basic design idea, some familiarity with the design, and finally a pre-assigned role in the user test. Nonetheless, time and efforts were still necessary to give all clinicians instructions on how to use the system before the first test-related appointments with patients, and, which proved highly challenging, finding ways to accommodate the test activities in the clinicians' busy schedules. As the user test was to be integrated into the normal work flow of the clinics, other staff in the clinics also became indirect participants: the secretaries assisting in rescheduling appointments, other technicians present in the background during remote and in-clinic follow-ups, and other clinicians – physicians and nurses – seeing the participating patients during the project phase for other, yet related medical issues. Besides receiving instructions, the five formally engaged clinicians' participation involved, with differentiation: creating clinical summaries for the participating patients; reading

patients' preparations before appointments; conducting follow-ups and consultations; and taking part in final interviews.

Besides patients and clinicians, I was as facilitator also a key participant in the user test. First of all, I undertook all coordination work: sketching the protocol, recruiting patients, coordinating appointments with patients and clinicians, and communicating with the software company about technical issues along the way. Secondly, I instructed patients and clinicians in using P-Record and, in practice, came to act as technical support on several occasions, with patients contacting me for additional instruction or trouble-shooting by telephone or by paying them extra visits. Thirdly, I accompanied the patients to all their appointments, keeping them company in the waiting room, being present during clinical encounters, and chatting with them afterwards. Moreover, I conducted two interviews with each of the patients (one as part of the first instruction visit and one rounding off their participation) and in total three final interviews with the clinicians (the cardiologists were interviewed in pairs, the technician individually). My work as facilitator contained a good deal of 'inclusion work' (Oudshoorn 2008; Rommes 2002): calling patients to remind them of upcoming appointments; clearing misunderstandings regarding appointments; immediately responding to occurring technical bugs or fall-outs; and generally encouraging patients as well as clinicians in using P-Record – whether extensively or marginally. At the same time, I took an ethnographic stance to the entire process – observing and documenting and leaving time and space open for informal conversations with the participants as we went along. In practice, this ethnographic practice came to serve as inclusion work as it seemed to further patients' motivation for participating. This illustrates how facilitation and fieldwork melted together, as I will discuss further in the following section.

The process was thoroughly documented, not least to allow me to later revisit all encounters with my attention no longer caught up in instruction and technical issues; the empirical material ultimately amounted to a comprehensive and diverse body of taped interviews, fieldnotes, memos, logbooks, video recordings of clinical encounters and instructions, photos, screen dumps, and project documents. The interviews (15 in total) were later transcribed, along with the video recordings of all clinical encounters and moments of instruction (app. 14 hours in total). During clinical encounters and

instructions, I also took notes and photos if I had the opportunity. After each activity related to the user test – whether it was an interview, a phone conversation, a visit to the clinic or something else – I wrote extensive fieldnotes. During the whole process I also kept a logbook over scheduled appointments, technical and logistical issues, and project communication and wrote ongoing analytical memos for each of the patient participants, gradually sketching user biographies and trajectories and developing analytical questions to pursue, as well as a consecutive memo with reflections on methodology. All entries in P-Record were documented by making daily screen dumps.

3.2.3 The user test as heuristic device

So how did this ethnographic experiment produce insights into practices of using e-health and the involvement of patients as information providers? While the actual analytical results are reserved for the papers, which also touch on methodological issues (Papers 3 and 4 in particular), I will here draw out the main benefits and challenges of the user test as a heuristic device – benefits and challenges that often intertwined. Overall, the user test and not least my role as facilitator provided me with countless opportunities to experience first-hand the work that goes into introducing new technology, implications of inviting participation, and challenges in existing relations and practices in the field of ICD-care.

First of all, valuable lessons were learned through what I in the beginning thought of as disturbing and time-consuming *practicalities*. I will give a few examples. When I called potential patient participants, most of them responded positively yet seemed little interested in P-Record; they primarily wanted to know what it would require from them and if I would be in charge of rearranging appointments with the clinics. In general, I seemed to be dealing with a group of patients that did not immediately celebrate the idea of adding e-health to their care scheme or the prospect of temporary interference and additional activities in an already complex and time-consuming care scheme, but nonetheless felt inclined to take part in research to help out when called upon. A letter from the wife of one of the patients who chose *not* to participate illustrates this stance; full of regret and apologies, the wife, on behalf of her husband, explains that since her husband attends follow-ups at several clinics and already takes part in another survey-based research project, “*participating in this research project will feel like a burden for*

him and therefor unlikely be of any help to you". She adds that the system will not likely be anything for her husband as he does not write Danish very well. This way, already the initial contact with patients, including 'non-participants', produced insights into negotiation and enactment of participation and patients' weighing-out of different 'projects', which especially have informed Paper 3. For instance, patients seemed to seek a balance between minimizing the complexity and extent of illness-related activities; helping out; complying when called upon; and, in some cases, a hope to get better care or spark change.

Another time-consuming, yet heuristically fruitful 'practicality' was the coordination with clinicians regarding test-related appointments. This was a complex puzzle of matching patients' and clinicians' agendas, which sometimes seemed like mission impossible. Besides reflecting the time pressure and organizational issues in the clinics, this coordination work also brought forth a limited interest in the project among clinicians. From informal conversations and later interviews, I gradually learned that this stemmed from the disappointment that the overall project had turned out to involve little clinical research, as well as from decreasing trust in the viability of P-Record, also adversely affected by the problem-ridden collaboration with the software company. While initially manifesting as a hindrance, or even resistance, the clinicians' half-hearted participation told me about core issues regarding P-Records' design and organizational feasibility and ultimately served as a reminder of the multiple agendas and subsequent fragility of innovation projects. It also illustrates the more general ethnographic premise that a field is something to be constructed, and the researcher is far from in control of this process. Yet, the resistances one meets are precisely those productive frictions from which we can start to understand what is at stake in the field (Winthereik, Berg & de Bont 2002; Zuiderent-Jerak & Jensen 2007). Likewise, the continuous technical problems with the system during the user-test, which I had to handle, illuminated the fragility of patients' motivation as well as issues of trust. When for instance patients' entries suddenly disappeared or a message sent via P-Record ended up with the wrong receiver, not only was it highly demotivating for the patients who had made an effort, it also raised doubts about data security that tapped right into media scandals and public debates about digitalization in the public sector.

Summing up, while the practicalities associated with my role as facilitator certainly have caused frustration and a nagging doubt about the methodological feasibility of my intervention, I overall perceive these practicalities as a valuable part of the experiment with participation. As Andersen et al (2010b) write in a reflection on the process of doing Participatory Design, practicalities can be seen as the “*performative actions and materials used to establish participation, [...] the tools used to plan and the class of work needed to be done before, during, and after participation takes place*” (p. 1) and therefore of utmost relevance to the researcher who is interested in, precisely, practices of participation.

A second benefit of (and challenge to) my role as facilitator was that it made me *part of the infrastructure of care*, that is, the situated, temporal infrastructure of ICD-care during the user test. This allowed me to experience first-hand the communicative practices in the clinics and between patients and clinicians and the coordination problems associated with a distributed care scheme. One example is the unforeseen coordination work I had to undertake in relation to the patient participant Ben. At the time when we initiated the user test, Ben was preoccupied with what he experienced as lack of communication or even misunderstanding between him and different clinicians, including his own general practitioner (GP), regarding concerns for his blood pressure. Subsequently, this also became the central issue in his use of P-Record and the related clinical encounters, as I describe through different analytical lenses in papers 2, 3 and 4. It was, however, not only in his entries in P-Record and during clinical encounters that these issues surfaced and shed light on his general concerns with what he perceived as a lack of coordination around his care. Ben’s way of involving me as facilitator in solving this lack of coordination proved even more analytically enlightening. At my first visit in Ben’s home, he immediately showed me a stack of papers related to his treatment: a referral letter for a blood pressure home monitor; a letter from his GP with the date of an upcoming appointment; and some earlier test results, asking me if I could somehow sort out the mess of what seemed to be conflicting appointments and decisions as to whether or not he should have a blood pressure home monitor. Throughout the user test, he continued to approach me as some sort of mediator between the clinics, someone who seemed to, at least for a while, provide him with that ‘one entrance’ to the healthcare system that he was looking for. Even if the infrastructure, that I became a

knot in, was thereby different from the normal infrastructure of ICD-care, it gave me a painstaking glimpse of the frustrations some patients (and clinicians) experience with the coordination and communication in a distributed care scheme.

During the process, I furthermore reflected on whether the challenges and frustrations I experienced in relation to contacting clinicians, long waiting times in the clinics, and delayed or cancelled appointments mirrored those of patients. Despite the different context of my contact with the clinics, my own experiences at least made me sensitive to the asymmetry between the different actors in a clinical setting and the frictions between what is experienced as important and urgent for staff and visitors respectively.

As with the practicalities associated with the facilitator role, the way I became part of the infrastructure of care proved to be a way to learn through frictions and the unexpected. Challenge became benefit, illustrating the methodological celebration in STS of intervention, as Hasu & Miettinen (2006) recapitulate it: “*it is in [our practical engagement] that objects and people resist our goals and purposes and force us to change our conceptions*” (p.13).

So far I have attended to the productiveness of my position as facilitator. A third issue, I will mention here, concerns the *outcome* of the user test. What kind of knowledge did the user test produce at large? How can we think of the status of the insights gained through this ethnographic experiment? A central aim of my research has been to gain understanding of e-health use practices and the associated patient-clinician interactions. In the case of P-Record, these practices were not already out there to be studied but had to be instigated through my study. This gives an experimental twist to my research aim: rather than studying how patients *are* involved as information providers with e-health, I have explored how patients *may become* information providers. This ‘becoming’ is of course intrinsically linked to the specific context of the user test and thus the particular experimental framework, where patients are well aware of their practices as bound to this situation. With inspiration from design research we might say that the use practices that unfolded were ‘rehearsals of a potential future’ (Halse et al 2010) in which the patients enacted participation not just in their own care, but also – vividly – in a larger, societal project for which the user test served as a mediator. I elaborate on this analytical point in Paper 3. In Paper 2, I do however pay less attention to the

experimental context and instead focus on the concrete moments of use, the way patients shaped information, and the encounters it sparked. These use situations were of course moments of experimenting, that is, of using the system for other purposes than to inform the immediate upcoming clinical encounter. Nevertheless, I will argue that the use situations still provide valuable insights into the work and implications of involving patient as information providers with e-health that did not seem to tie closely to the experimental nature of the user test. This is not to say that this knowledge is not situated – it sure is, as is all knowledge. It is a premise of knowledge production, not least ethnography, that the situation cannot be taken out of the equation. We can never claim generalizability of the insights produced. Consequently, generalizability is not a virtue or goal of the kind of pragmatic and critical ethnography that STS studies most commonly rest on. Instead, the knowledge we produce is to be judged by its effects: how does it allow us to think differently? Or, pushing this pragmatic ideal towards a design-orientation and situating it in my specific project: how can the knowledge produced inform design and broader discussions on e-health and patient participation by bringing forth other scenarios than the once most commonly articulated in e-health innovation?

3.2.4 Ethical considerations

While I with the previous section have aimed at providing epistemological justification for the user test as ethnographic experiment, the ethical implications of the user test should also be discussed. Some of these implications have been hinted at above as challenges of enrolling and retaining patients and clinicians and as heuristically productive frictions. However, analytical justification does not imply ethical justification, and throughout the user test I have sought to constantly balance analytical and ethical concerns based on a context-sensitive approach, or what Hastrup has termed ‘praksisetik’ (Hastrup 2009). This first of all entailed complying with common standards for ethical conduct of ethnographic research which can basically only be reduced to the principle of ‘doing no harm’ to be interpreted and enacted as a situated matter through the research process (also discussed by Mohr 2014). Obtaining informed consent, providing anonymity and confidentiality, and ensuring some level of transparency in the research process are often part of an ethical research conduct, yet not necessarily always, and in any case never what ethics can be reduced to (Hoeyer,

Jensen & Mohr 2011). The user test was in this respect no different from other kinds of ethnographic research.

Some formal ethical requirements were dealt with before the user test was initiated. Following Danish law on research ethics, formal ethical approval can only be obtained for biomedical research projects²³. Qualitative research projects like mine only fall under two kinds of regulation: 1) the Danish Data Protection Act, which lays out principles for the treatment of sensitive personal data, including obtainment of approval of the research project's protocol for data management; and 2) the Danish Health Act's paragraph concerning qualitative health research, which prescribes the obtainment of approval of The Danish National Board of Health for the disclosure of sensitive personal data to researchers undertaking studies that do not require formal ethical approval. In both cases, my research – including the user test – was covered by the approvals obtained by the CITH-project under the responsibility of the research leader and the leading clinicians, respectively.

The first 'practical' ethical concern was related to the recruitment of patients. While I was eager to enroll participants for the user test and was encouraged by the clinics to contact eligible patients by telephone, I was also concerned about this proactive recruitment strategy and made an effort to not be persuasive and in any case not make any appointments with patients before they had received written information. I further underscored the possibility of opting out any time. I already at this early stage felt uncomfortable with the invitation I was posing to patients, although this was only to mature as an analytical insight later on (see Paper 3). At the time of recruitment, I had already sensed clinicians' hesitations towards the user test and P-Record and did not expect the user test to lead to actual changes in the clinical practices, let alone to the implementation of P-Record. I did not directly share these speculations with patients, but nevertheless tried not to spark unrealistic expectations and stressed the temporary and experimental nature of the user test.

The management of expectations became a persistent concern. During instructions, I again felt compelled to underscore the experimental nature of the practices taking place,

²³ The Danish Act on Research Ethics Review of Health Research Projects, section 14, available at www.cvk.sum.dk/english/actonabiomedicalresearch.aspx (accessed January 16, 2015).

stressing that I did not know how clinicians would respond (what they could expect) and reminding patients to take up urgent medical matters with the clinicians as they would otherwise do and not use the system for this. At the end of the user test, managing expectations – and disappointments – once again surfaced as a concern. While most of the patients agreed with the terms of a predefined project period and expressed satisfaction with the prospect of receiving an update on the outcome of the project later on but otherwise terminate their participation, one patient did not easily accept this. As I discuss in more detail in Paper 3, he had taken on the role of partner and co-designer in the project and now expected to be part of further deliberations and even decisions regarding the fate of P-Record or other e-health innovations in ICD-care. This points to a central ethical concern for innovation-oriented research, namely, what it is we invite participants/users to. This is an ethical concern that mirrors and is closely linked to the broader question of what it is patients are invited to when invited to participate and thereby central to the theme of this thesis.

The concern for expectations is linked to a broader concern for how to give back to the field and the research participants. As I show in Paper 3, several of the patients had previously participated in other research projects and some were disappointed with the lack of feedback, on their own medical conditions as well as the overall outcome of the projects. This alerted me to my own use of patients as ‘human resources’ for research, considering how I could return their efforts, and took concrete measures such as sending a follow-up later after a few months with a summary of the insights gained and a status for P-Record and the CITH-project, also inviting patients to contact me if they were interested in receiving further updates. None of the patients replied. As the participating clinicians were project partners and later in the process co-authored an article about the user test (paper 4), I worried less about how I could ‘give back’ to them as research participants; our relationship was of a different collaborative manner. Besides the concrete things one can do to follow up on a fieldwork and share results, ‘giving back’ is part of a more complex question of contribution – to the field, to research, to society. I will return to this in Section 3.4.2, where I describe my dissemination of results, which is further elaborated on in Chapter 4’s discussion of how the papers constitute different contributions and forward-looking interventions.

3.3. Additional fieldwork

Before and after the user test, I conducted additional fieldwork at the involved heart clinics. This can be divided into two parts. The first part consisted of participant observations at the device clinic and the local hospital's outpatient heart clinic where I followed cardiologists and technicians in their daily work related to ICD-care. At the device clinic, I was present during: an initial consultation; two implementations of ICD's; at five follow-up consultations before discharge after implementation; two morning conferences at the ward; 13 ICD and pacemaker follow-ups; and three days of remote follow-ups. At the local hospital, I followed one of the two cardiologists who were also involved in the user test over the course of one day's consultation where he saw ICD patients as well as other heart patients (eight patients in total). This part of the fieldwork was undertaken to inform the user test by providing background information about the ICD-care practices that P-Record would be part of. Inevitable, it also involved numerous informal conversations with clinicians about P-Record and the overall research project; the different clinicians' reactions to my presence, the project, and the prospect of implementation of P-Record provided valuable insights into the complexity and local politics of introducing new technology and potentially reconfigure practices of patient involvement. The fieldwork was documented by fieldnotes and further processed through consecutive analytical memos.

The second part of the additional fieldwork was intermingled with the first, but only took place at the device clinic and, in addition, at the related outpatient clinic, specialized in hereditary cardiac disorders and thus receiving not only ICD-patients but heart patients and relatives from a large area. The purpose of this part of the fieldwork evolved gradually. It started out as a 'collateral' part of the exploratory fieldwork for the user test, in which I between ICD-related practices in the device clinic encountered practices related to short-term heart monitoring. However, an interesting parallel between ICD-care and P-Record emerged: the use of paper diaries filled out by patients to contextualize the data obtained by home monitoring devices such as Holter-monitors and event cards. This influenced the reformulation of my initial research interest to include an exploration of existing 'mundane' practices and devices of patient participation in heart care in order to provide contrast to but also to situate P-Record

within a larger landscape of devices with similar capacities from which relevant lessons might be learned. After this reorientation, I conducted an additional two weeks of participant observations in the device clinic focusing only on short-term monitoring. I followed the technicians' work of handing out devices to patients and analyze the incoming data and I attended a total of 16 consultations conducted by cardiologists at the outpatient clinic in which the short-term monitoring data was used. During this work, I had numerous informal conversations with technicians and cardiologists about their work practices, with special focus on how they used the paper diaries. As part of my observations, I encountered approximately 50 different paper diaries. Like in the first part of the additional fieldwork, I took detailed fieldnotes and kept consecutive analytical memos and furthermore documented practices and devices by photo after agreement with the involved clinicians but never when patients were present.

3.3.1 Still invited? A few notes on ethics and access

This leads me to a few common notes on access and ethics in the additional fieldwork. I was granted access through the cardiologists who also participated in the user test as well as the overall research project. Their commitment to the project meant that my additional fieldwork in the clinics to a large extent was seen as 'part of the package' and I experienced no rejections or even resistance when I approached the cardiologists, requesting to follow different activities. However, when at the device clinic, other clinicians were present that had not directly granted me access. While it was unclear to me, if these clinicians had been informed of, not to say actively agreed to, my presence, I initially made efforts to introduce myself, my project, and ask for permission to follow their work whenever I encountered new staff members. For this purpose, I had with me copies of an information sheet presenting my project, aims of the current fieldwork, and contact information; I also put up these leaflets on the clinics' notice boards. The information sheets were also meant for the patients that I would come in contact with. Yet, my ideals of ethical research quickly proved practically unfeasible. First of all, being at a university hospital and put in a hospital uniform, I blended in with a flow of other 'insider guests' such as medical students and interns as well as representatives of the medical industry. Moreover, since the CITH-project had already been running for three years, the staff seemed to have gotten used to having design researchers hanging around, observing their practices. No one seemed to pay much attention to me, let alone

resist my presence. This also seemed to be a result of the clinic being a very busy place: introducing my project and asking for permission to join certain activities often seemed to be an unwelcome interruption. Eventually, I took a pragmatic ad hoc approach to negotiating access and obtaining content, making appointments with leading staff members from day to day about my presence, trusting them to inform their colleagues, and when in the clinic, sensing from situation to situation if asking permission or giving information was required and *welcome*.

In relation to informing patients, the situation required a similar context-sensitive approach. I entered the clinics determined to comply with the earlier mentioned common norms for good ethnographic research such as ensuring visibility and transparency about the nature of my participation in the field and obtaining consent from anyone actively partaking in the situation, not least clinical encounters. However, I found myself in unclear ethical territory as the clinicians I followed all took charge of the interactions with patients, briefly introducing me as a student or researcher ‘who is just looking a bit’ (or with similar wording), in most cases leaving me no room for introducing my research, handing out written material, and asking for permission. While this was initially a cause for concern, I gradually came to appreciate this conduct as not just pragmatic but also partly a result of exactly ethical concerns on behalf of clinicians who did not want to bother their patients with too much information about a research project that intervened very little in their care. It seemed that the clinicians and I, without much negotiation, found a shared context-sensitive approach, conditioned by my overall acceptance of the situations in which I took part as being within the realm of their professional responsibility.

3.4 Analysis and dissemination

I end the methods chapter with a description of how I moved from this diverse fieldwork to written text. A retrospective account of one’s analytical work is inevitably reductionist and artificially linear; the analytical paths one actually travels are messy processes of association that are far from fully tangible to one self. What I can describe, are the analytical devices I have employed, the overall analytical iterations that I have gone through, and the different products I have arrived at.

3.4.1 Analytical filtration work

I suggest that my analytical process, just as the practices of using P-Record, can be described as analytical *filtration work* unfolding in dialogue with the empirical material, the analytical devices I have employed, and the larger projects that I have sought to feed into. Conceptualizing the analytical process as filtration work serves to underscore two points: first, that analysis is about selection – of constructing particular perspectives rather than others and, second, that this process is at the same time goal-oriented and dynamic, deliberate and unruly.

Upon finalizing the user test and the additional fieldwork, I had a diverse and rich empirical material in front of me consisting of transcriptions of all interviews, instructions and clinical encounters during the user test supplemented with video recordings, photos, and screen dumps, fieldnotes, logbook, and memos. Analysis had of course already started long before I started writing. During my fieldwork, questions and themes formed in continuous dialogue with the practices I studied and were part of, and this analytical filtration work had in return shaped my empirical work. This reflected in how I gradually developed an interest for other participatory devices in heart care and concentrated the additional fieldwork on short-term monitoring practices and the use of paper diaries. The dialogue between research interests and empirical practices also reflected in how I continuously adapted my approach to interviews and informal conversations with participants during the user test towards an ever more open and associative style with no predefined questions, but guided by themes that had emerged – overall as well as for each participant.

When initiating the actual writing process, my initial research questions had thus faded and been replaced by an assemblage of puzzling themes and situations, which overall had to do with the ambiguity of what had unfolded and been articulated during the user test. While both patients and clinicians had expressed moderate expectations to P-Record, some patients ended up overtly disappointed – with the system and the clinical encounters that were part of the user test. I was thus first of all interested in understanding the source of this disappointment and how it related to the design and use of P-Record. To unpack this question, I tested different analytical tools inspired by other studies of e-health use, whereby I found the notion of invisible work most productive.

Yet, this conceptualization did not provide sufficient understanding, and I looked further to information and communication theory from where I developed the notion of dialogic filtration work that seemed able to unpack and encapsulate the dynamics of expectations and disappointments in the use of P-Record (Paper 2). This analytical filtration work had however also left something out: the context of the user test and how the use practices could also be understood as overall enactments of participation at the intersections between treatment, research, and innovation, which became the topic of the next stage in my analytical work (Paper 3). The focus on enactments of participation called for analytical devices that could help me grasp the relation between use practices, patients' deliberations during the user test, and the more overall projects that seemed to be at play. I saw this reflected in the notions of material participation and tactics.

Meanwhile, I had started working on a joint paper in the CITH-project (paper 4), guided not by a puzzling analytical theme, but by an interest in developing a specific kind of contribution: a translation of the ethnographic insights into design recommendations. Working backwards from this ambition, the analytical concepts were chosen from their ability to encapsulate the common insights produced within otherwise very different theoretical frameworks. As the writing of paper 4 ran parallel to my writing of both Paper 2 and Paper 3, the relation between the different analytical processes was inevitably dialectic, although Paper 2 and Paper 3 primarily informed Paper 4 and only to a limited degree did it happen the other way around. After these three interlinked writing processes, I turned to what had stayed in the background, yet still gradually matured into an analytical idea: my interest in existing devices and practices of involving patients as information providers in heart care. Short-term monitoring seemed to mirror the arrangement we had temporarily created with P-Record in ICD-care, and sparked by a wish to find a common language to describe these otherwise different arrangements and draw lessons from one to the other, I started a simultaneous process of searching for adequate and productive concepts and analyzing the additional fieldwork. This work resulted in Paper 1. Importantly, this account of my analytical work reveals a different order of papers in the writing process than how they are presented in the thesis. The order of presentation is chosen according to my research questions and the way they in concert allow a journey through existing and 'potential' practices and devices of involving heart patients as information providers. I will unfold

the synergies – and differences – between the final papers in much more detail in Chapter 4.

In the development of all of the papers, my concrete analytical work consisted of iterating between reading transcriptions and fieldnotes (or watching video recordings), taking notes, developing initial themes, coding and recoding the written material, writing memos, and in some cases discussing snippets of the empirical material and my preliminary analysis with peers. Peer-discussions were of course most prevalent in Paper 3 and Paper 4, where I worked with co-authors. I did not discuss my analysis with the patient participants; inviting them to take part in this process after the termination of the user test simply felt inappropriate and intrusive – as asking for too much. Accordingly, I chose not to discuss my analysis with the participating clinicians either, as I believe this would have entailed a problematic asymmetry in the ‘rhetorical authority’ (to paraphrase Markussen & Olesen 2007) of patients and clinicians.

3.4.2 Multiple interventions, one overall response to the invitation

The analytical filtration work was also guided by overall considerations of whom I wanted to speak to. As hinted at above, this was vividly the case in the development of paper 4, but considerations about which fields I wanted contribute to also played a role when writing the remaining papers and in the choice of other ways of disseminating results. To differentiate my contributions, I find it useful to once again employ Jensen’s (2012) typology of different ways of intervening by invitation. My engagement during the user test, where my role was to hold things together, engage users, and mediate, would fall under the category ‘intervention-by-composition’. With the papers, I practice what Jensen calls ‘intervention-as-performance’, which refers to the basic point that any description is an intervention, and to some extent ‘intervention-by-interferences’, referring to the classical STS-position of studying up and inferring by critique. With Papers 1-3, I seek to contribute to the fields of research from which I also depart: STS and CSCW. This clearly shaped the critical orientation and analytical repertoires of the papers. With paper 4, I seek to contribute to design research, and in particular the field of Medical Informatics, by translating description and critique to prescriptions for e-health design. I thereby move closer to practicing ‘intervention-as-availability’, that is, to study by invitation and make one’s analysis available to the people one directly or

indirectly is called on to inform: designers, decision-makers, and practitioners. The contributions of the papers will be elaborated on in Chapter 4.

As mentioned above, I also disseminated my results at a seminar for partners in the CITH-project, including the software company and here more vividly practiced ‘intervention-as-availability’. The seminar was a first attempt at making the insights from the user test concrete and ‘practically relevant’, while still allowing the complexity and contradictions of use practices and participants’ deliberations to come forth. With numerous examples from the user test of use situations in home and clinic, quotes and portraits of the participants, I tried to stay true to the ethnographic character of my study and an analytical granularity, which ultimately prevented me from arriving at unambiguous conclusions as to the feasibility of the system. This was not my aim, either. In this ‘making-available’ of my analysis, I sought to maintain the status of the ethnographic insights as interesting in their own right – to stick to the, perhaps most important, methodological principle in my research, namely to treat the user test as an ethnographic experiment with e-health and patient participation, and to *not* reduce ethnography to a tool for design and evaluation of particular applications.

4. Outcome: a four-part ethnography of e-health

In this concluding chapter, I introduce and discuss the four papers that, together, constitute my ethnography of patient-involving e-health in heart care. First, I give a brief summary of each of the four papers, followed by a reflection on their order and the analytical synergies and frictions between the papers. I then present the overall contributions that the papers, in concert, make and the implications for research and innovation, respectively. Finally, I arrive at an overall conclusion of my study.

4.1 Introducing the papers

All papers address the tension between invitation and answer when patients are invited to participate, but with divergent foci, partly in terms of the empirical objects, but especially in terms of the applied concepts and analytical aims. In this section, I summarize the papers and, subsequently, aim to clarify how the papers relate to and how they differ from each other.

4.1.1 *Summary of papers*

Paper 1, “*Inviting information, inviting patients: participatory scopic devices in remote heart monitoring*” explores current heart monitoring arrangements. The paper shows how these arrangements involve interlinked practices of enhancing the clinical scope and inviting patients to participate that resemble those that e-health is envisioned to facilitate. The empirical focus is on the use of paper diaries to obtain contextual information from patients in short-term heart monitoring practices. The paper describes how paper diaries work as *participatory scopic devices* and the challenges that they pose to patients and clinicians, most noticeably the problem of how to define relevant information as well as how information should be responded to. The paper argues that e-health can be understood as a continuation rather than revolution of existing ‘scoping’ and ‘participatory’ practices in heart care, and that studying these practices provides a valuable glimpse into the possible workings and implications of e-health. Paper 1,

thereby, answers research question 1: *How are patients invited and equipped to provide information in existing practices of remote heart monitoring; and what can we learn about the challenges of involving patients as information providers from these existing practices?*

Paper 2, “*Involving patients with e-health: the dialogic dynamics of information filtration work*”, explores how patients and clinicians use and interact with P-Record as an information ‘filtration device’. It shows how patients conduct inherently communicative work when using P-Record; work driven by and sparking both negative and positive anticipations of entering a dialogue when using P-Record, including specific perceptions of what would constitute a good answer that often counter with clinicians’ perceptions. The paper proposes the concept, *filtration work*, as an analytical tool that can help bring forth the invisible work and dialogic dynamics involved when patients are invited to become information providers with e-health and explain the sources of the subsequently unmet expectations. Paper 2, thereby, answers research question 2: *What kind of work does it require to participate as information providers with e-health; and how does this work affect how patients and professionals evaluate the specific tool?*

Paper 3, “*Technologies and tactics of participation: how patients shape their engagement through e-health*”, demonstrates how P-Record and the user test, together, pose an ambiguous invitation to participate to patients, and how patients attempt to meet this invitation by enacting participation along the lines of different *tactics*. These tactics cut across the entangled practices of research and care, as well as the concrete situation of the user test and their everyday lives as heart patients. The paper identifies three different tactics that the patient users of P-Record deployed, designating these as: *activism*, *collaboration*, and *compliant citizenship*. The paper shows that patients who enact a participatory tactic that allows them to reorient towards larger societal rather than situated and individual purposes, are better able to cope with the ambiguous invitation of P-Record and less disappointed with the outcome. Paper 3, thereby, answers research question 3: *How do patients, through e-health, respond to an overall invitation to become participating patients; and how do the ways in which they enact*

participation influence their experiences of the specific tool? The paper is co-authored by Henriette Langstrup.

Paper 4, “*A design rationale for aligning concerns in e-health*”, shows how the disappointment or satisfaction among P-Records’ patient-users, overall, depends on the alignment of concerns between patients and clinicians. Translating this insight into a design rationale, the paper suggests that in order for an e-health service to be viable, it must be targeted to support communication about concerns that are already *meaningful* to both patients and clinicians, *actionable*, and *organizational feasible* – or *enable* concerns to become so. The paper deliberately formulates ethnographically informed design recommendations that are rather general and tentative. These recommendations are based on the argument that what can become a meaningful tool must be explored *in situ* and continuously renegotiated – not least, as a consequence of the inherently open nature of an invitation to participate. Paper 4, thereby, answers research question 4: *How can the local ethnographic insights into the ways in which P-Records’ users responded to the invitation to participate be translated into recommendations for e-health design, in heart care and beyond?* The paper is co-authored by Tariq Andersen, Jørgen Bansler, Finn Kensing, Jonas Moll, Troels Mønsted, Olav Wendelboe Nielsen, Helen Høegh Petersen, and Jesper Hastrup Svendsen.

4.1.2 Order of papers

In the thesis, the order of the papers allows for an *analytical* progression to emerge: from sketching the field and setting a research agenda, to unpacking practices and critically engaging with discourses in the field, and, finally, to formulating prescriptions. The order of the papers also represents a *temporal* progression from exploring mundane devices and established practices, through experimenting with a new technology and disturbing practice, to laying out a framework for future design. Hence, Paper 1 *situates* e-health for ICD-patients in the broader field of patient-involvement in heart monitoring, which includes other devices for obtaining information outside the physical realm of the clinic, and points to issues of particular analytical relevance when studying such devices – be it paper diaries or e-health. Paper 2 then *zooms in* on e-health and the experimental use of the specific device, P-Record; unpacking the intricacies and dynamics between expectations and use practices. Paper 3

also deals with the practices of using P-record, but places P-Record in a larger *political context*. It does so by focusing on P-Record as a *participatory device* and the role of the diverse participatory projects that can be said to ‘rally’ in the user test. Allowing the thesis to end on a high note, the final paper – Paper 4 – uses the case of P-Record to *prescribe* a design rationale for patient-involving e-health that takes into account the importance and challenges of aligning patients’ and clinicians’ concerns.

As shown in the previous section, the order of the four papers also reflects in the order of research questions; thus, step by step, the papers bring me closer to answering the overall research question and fulfilling my aim to both *understand* and *inform*. In the next section, I discuss this heuristic progression in more detail, by reflecting on the analytical synergies and frictions between the papers.

4.1.3 Synergies and frictions between the papers

Each of the first three papers proposes a unique conceptualization of e-health and e-health use. This raises three questions: Why the need for three different conceptualizations? How do the papers and their applied conceptualizations relate? And which insights do they, in sum, allow me to bring forth? The short answer to the first question is that the concepts are chosen to allow me to pursue different analytical goals. Following the structure of the theoretical framework of the thesis (Chapter 2), these analytical goals can, overall, be described as: sketching and situating the *arrangements* of e-health in heart care, unpacking the *work* of using e-health, and exploring the *participatory projects* of e-health. In addition, Paper 4 proposes yet another conceptualization, this time with the aim of informing design. (See Table 1 for an overview of the conceptual contributions of the four papers)

Answering the second question, how the papers and their concepts relate, is also an elaboration of how the papers pursue different analytical goals. In Paper 1, I introduce the notion of *participatory scopic devices* inspired by Cetina’s (2009) moderation of symbolic interactionism. I do so in order to allow for a productive analytical alignment between P-Record and other existing practices and devices for patient-involvement in the heart monitoring arrangements it was to be part of. The notion of *participatory scopic devices* makes visible capacities, rather than specific technical properties, and,

thus, allows us to draw out implications of existing devices that are likely to be relevant for emerging devices as well. In Paper 2, I then zoom in on P-Record's specific participatory capacity of involving patients as *information providers*, including precisely the problem of how to define relevant information as well as how receivers should respond. Paper 2, thereby, follows in line with the insights from Paper 1. Yet, in order to further unpack the challenges associated with providing and receiving information, I draw on the notion of invisible work (Star & Strauss 1999) as it particularly relates to information production in healthcare (Berg 1996; Heath & Luff 1996; Oudshoorn 2011) and on concepts from dialogism (Bakhtin 1986). Informed by these theoretical resources, I conceptualize P-Record as a *filtration device* and the use practices as *dialogic filtration work*, showing how P-Record supports clinicians' filtration work more readily than patients'. The notion of filtration work sheds light on the linkages between the resources patients have to draw on when providing information and the anticipations of particular kinds of responses that arise in the process, and thus serves as a tool not only for exploration, but also explanation.

Paper 3 introduces yet another conceptualization of P-Record, this time simply as a *participatory device* (Marres 2011), and thereby highlights how P-Record materializes an overall participatory strategy of modern healthcare (Prainsack 2014). Where Paper 2 focuses on the way users try to appropriate P-Record as a tool for local interactions, thus 'rehearsing' potential future care practices with e-health, Paper 3 attends more thoroughly to the specific context of use – the user test – by focusing on P-Record as a tool for participation in both care and research/innovation. Thus, of the four papers, Paper 3 addresses, most explicitly, the participatory dimension of e-health and proposes a conceptualization of the patient users' practices as *participatory tactics*, inspired by de Certeau (1984), which affords a critical look at the ubiquitous – and deeply political – participatory project in healthcare and e-health in particular. Together, Papers 2 and 3 illuminate the ambiguity of the invitation that P-Record poses, and how patients' and clinicians' perceptions of what P-Record is a tool *for* differ fundamentally. Common for patients' use practices is that they built on and entail dialogic dynamics and, furthermore, are guided by different participatory tactics. While the dialogic dynamics involved in using P-Record only lead to a general disappointment with the system and

how it mediates between home and clinic, the patients' participatory tactics allow some patients to formulate other, more meaningful purposes of P-Record and the user test.

Paper 4, then, represents an attempt to, indirectly, translate the insights of the previous three papers regarding the workings and implications of tools that invite patients to participate into a rationale that may directly inform design. Theoretically, the paper draws on insights from medical phenomenology (Charon 1992; Toombs 1993), which, in combination with methodological inspiration from Participatory Design (Clemensen et al 2007; Simonsen & Robertson 2013), is used to formulate a design rationale for *aligning concerns* in e-health. This choice of analytical resources serves to bring the paper into dialogue with the field of Medical Informatics, without conflicting with the insights of the remaining three papers. In particular, Paper 4 echoes the empirical insights of Paper 2; what are conceptualized as divergent *communicative projects* (Linell 2001) in Paper 2 are denoted divergent *concerns* in Paper 4. In general, Paper 4 echoes the remaining three papers' basic ontological assumptions: drawing on Participatory Design (Pilemalm & Timpka 2008; Simonsen & Robertson 2013) to stress e-health design as ongoing, local processes of negotiation and adaptation, Paper 4 proposes a design rationale that takes into account the situated, fluent and mutually constituent ontology of technologies and practices (Callon 1986; Law 1994; Latour 2005; Moreira 2000).

As mentioned in the methods chapter (Section 3.4.2), the papers were neither written in the order in which they are presented in the thesis, nor were they written in a strictly successive order. This means that there is only limited conceptual integration between the papers and, anyway, no clear accumulation of concepts from Paper 1 to Paper 4. Nevertheless, I will argue that the concepts I propose in each of the papers, in concert, form a coherent conceptual framework for studying patient-involving e-health. All four papers depart from a sociotechnical approach and, thus, share an orientation towards the interdependencies between materiality and social practice in the use of e-health and other patient-involving devices. Their different conceptual entries to the same empirical field and, largely, to the same empirical material, make the papers complementary: in concert, they bring forth a series of closely interlinked dimensions of e-health,

particularly in heart care, and span from exploration through explanation to critique and, ultimately, prescription.

PAPER	RESEARCH QUESTION	ANALYTICS	CONCEPTUAL CONTRIBUTION
1. <i>"Inviting information, inviting patients: participatory scopic devices in remote heart monitoring"</i>	1. How are patients invited and equipped to provide information in existing practices of remote heart monitoring; and what can we learn about challenges of involving patients as information providers from these existing practices?	E-health as socio-technical arrangements	E-health as 'participatory scopic devices'
2. <i>"Involving patients with e-health: the dialogic dynamics of information filtration work"</i>	2. What kind of work does it require to participate as information providers with e-health; and how does this work affect how patients and professional evaluate the specific tool?	E-health use practices as work	The use of e-health as '(dialogic) filtration work'
3. <i>"Technologies and tactics of participation: how patients shape their engagement through e-health"</i>	3. How do patients, through e-health, respond to an overall invitation to become participating patients; and how do the ways in which they enact participation influence their experiences of the specific tool?	E-health as participatory projects	The use of e-health as 'participatory tactics'
4. <i>"A design rationale for aligning concerns in e-health"</i>	4. How can the local ethnographic insights regarding the ways in which P-Records' users responded to the invitation to become participants be translated into recommendations for e-health design, in heart care and beyond?	(medical phenomenology; Participatory Design)	E-health design as a matter of 'aligning concerns'

Table 1. Overview of the four papers: research questions; analytics; and conceptual contributions.

4.2 Contribution and implications: a three-fold intervention

My contributions can be divided into three parts: contributions to e-health research, contributions to e-health design, and contributions to the overall participatory project in healthcare. These contributions can be described as different kinds of interventions, some intended and some unintended, but ultimately, all as productive ways of shaping the field of e-health and patient participation.

4.2.1 Intervening in e-health research

With Papers 1-3, I contribute to research concerning the social and organizational implications of e-health. Particularly, the papers add to accounts offered by STS and CSCW of new patient-involving technologies in healthcare provision – technologies that are, here, typically termed 'telemedicine', 'telehealth', or 'telecare' (Bruni & Rizzi

2013; Langstrup et al 2013; Mort et al 2003; Oudshoorn 2011; Piras & Zanutto 2010; Pols 2012; Roberts et al 2012; Schillmeier & Domènech 2010; among others). As described in the theory chapter, I draw on valuable insights provided by this body of literature about the fluent ontology and ‘unruliness’ of such technologies: that is, how they gain different identities through the different sociotechnical arrangements and use practices that they become part of; how they create unforeseen effects; and, importantly, the different kinds of often invisible work they entail for patients as well as clinicians.

In return, I contribute three new conceptualizations of e-health and e-health use that, in concert, facilitate a closer engagement with the workings of e-health devices as specifically *participatory* devices. My analysis of the use of e-health and similar participatory scopic devices in heart care reveals how the use of such devices involves a challenging *filtration work* on the part of both patients and clinicians. This filtration work requires particular resources, sparks expectations, creates informational overflows, and invokes questions about the responsibilities of both providers and receivers of information. Moreover, looking at e-health as participatory devices that are invested with diverse, political *projects* and often used in the context of research and innovation projects, facilitates a critical view of the normative project of patient participation that is linked to e-health. These insights regarding the interactional workings and participatory projects of e-health flag attention to the intricacies of (inter)personal, political, and material dimensions in e-health use.

The thesis also contributes to more applied and normatively oriented studies of e-health and patient participation (Brennan et al 2010; Das & Svanæs 2013; Gibbons 2008; Kvedar & Kibbe 2009; O’Grady & Jadad 2010; among many others). It, first of all, does so by flagging attention to the intricacies of (inter)personal, political, and material dimensions in e-health use, which have received limited attention in this wider field of applied research. For instance, empirical insights into how the materiality of e-health may support the filtration work of one group of users more readily than others, and which overflows e-health as a filtration device may create, can help shed light on the difficulties of stabilizing e-health devices as ‘win-win solutions’. Second, the thesis invites researchers committed to furthering patient participation, with or without e-health, to bracket attempts to define and measure participation and, instead, explore the

multivalency of participatory practices by attending to the practical and normative variations in how patients respond to invitations to participate and what patients' different responses produce. This may facilitate a better understanding of the challenges and implications of 'participatory healthcare' – for patients, clinicians, and the healthcare sector at large.

As noted in the theory chapter, STS, CSCW as well as the broader field of research into e-health and patient participation widely promote qualitative methods for studying e-health as technologies embedded in particular social contexts. However, I contribute a specific methodological approach for qualitative e-health research: I demonstrate how a very direct engagement in test activities may be utilized as an *ethnographic experiment* (Danholt 2008; Mann et al 2011). I suggest the ethnographic experiment as a way of turning the 'project-ness' (Langstrup 2010; Law & Singleton 2000) and immaturity of many e-health practices into a methodological resource. I propose that approaching test activities as ethnographic experiments is also a productive way of doing research by invitation that allows for both descriptive and prescriptive contributions. In the following section, I elaborate on my prescriptively oriented contribution, aimed at e-health design.

4.2.2 Intervening in e-health design

Paper 4 contributes directly to fields invested in e-health design with a combined analytical and methodological framework for designing patient-involving e-health. By including this prescriptive contribution in the thesis, I go beyond my ambition to employ the user test as an ethnographic experiment that produce description and understanding of the workings of e-health. However, it can also be seen as a return to the typical evaluative aims of user tests and thus in line with the 'native' perceptions of what purposes a user test serves in innovation-oriented fields such as Medical Informatics and Information Systems Design and the associated view of ethnography as an instrument for design (discussed by e.g. Blomberg & Karasti 2013). This view is also, to some extent, shared by some STS and, in particular, CSCW scholars, who would argue for the value of STS ethnography when this is taken further to prescription that intervenes into society (Hess 2001; Timmermans & Berg 2003; Zuiderent-Jerak 2010).

As I discuss in the methods chapter, there are many ways of defining an invention, and I do not believe the design recommendations of Paper 4 to be ‘more’ of an intervention than the ethnographic descriptions offered by Papers 1-3. However, Paper 4 delivers a particular kind of intervention for a particular audience for whom I (together with my co-authors) have undertaken a strategic translation of the ethnography into prescription. Importantly, this prescription is not a list of design requirements, but rather a sensitizing framework that underscores the situated, fluent and socially embedded ontology of technologies, and invites designers to enter an iterative and participatory process of not just identifying, but also facilitating negotiation of the problems that a given e-health tool is thought to be the solution to. Importantly, such a process should not be taken to lead to ‘finished’ solutions. In practice, design processes are not definite since any tool to support cooperative work will spark recursive articulation work (Schmidt & Simone 1996), and any formalization of practices will spark resistance and reconfigurations (Star & Strauss 1999; Suchman 1995), to put it in the terminology of CSCW. In sum, I take the contributions of all four papers to feed into the same overall knowledge project: to gain a better understanding of e-health and patient participation – as a matter of concern, but also as a matter of fact (Latour 2004) with which we can constructively engage.

4.2.3 Intervening in an overall participatory project in healthcare

Finally, the thesis intervenes into the overall participatory project of healthcare. It does so through the scholarly interventions mentioned above and in the form of the four papers. In addition, I have intervened through my research *practice*. While any ethnographic fieldwork intervenes in the practices it studies, the ethnographic experiment I have conducted is particularly performative. As the user test asked patients to rehearse a potential future (Halse et al 2010), including future care practices and future patient roles, expectations or, at least, *imaginings* of this future were shaped. Moreover, what was rehearsed was not a far-out future, but an already heavily articulated, and thereby ‘partially existing’ (Jensen 2010; Latour 1999), version of healthcare. Patient-involving e-health does not figure in the public discourse as a future utopia, but rather as part and parcel of a transformation we are already in the middle of. Acting as a facilitator of the user test and inviting patients to *participate* in the shaping

of new *participatory* healthcare practices, I can – in a double sense – be said to have acted as a ‘participation entrepreneur’ (Bogner 2011). Largely unwillingly, I may thereby have contributed to a project-based, technology-focused, and participation-oriented healthcare system – and to creating certain expectations thereof among patients (and clinicians). *Studying* change and *instigating* change have become interlinked undertakings in my research practice.

This calls for ethical reflections on the possible wider impact of my particular engagement in transforming healthcare; as Zuidenrent-Jerak (2007) notes without reference to a specific field, when undertaking innovation-oriented interventions one should “*take seriously the theoretical, practical and political consequences of such ongoing transformations.*” (p.233). Here, I want to bring forth two issues that call for further reflection as the results of my study travel onwards to different sites:

First, while making visible patients’ participatory practices may incite designers and practitioners to seek to formulate clearer invitations and facilitate alignment of expectations between different users of e-health, it may also lead to problematic formalization and further capitalization of patients’ participatory practices. For instance, it will be a challenging balancing act to design for the support of both patients’ and clinicians’ filtration work without impoverishing the richness of information and patients’ possibilities for raising highly individual and atypical concerns. Moreover, the three specific participatory tactics that I identify in the use of P-Record should be read as *situated* accounts that point to the multivalency and unpredictable nature of patient participation, and not as a universal typology of participation that can be used to foresee and design for different modes of patient participation. Therefore, I wish to encourage cautious practice-oriented translations of the thesis that take into account the inevitable tension between structured invitations and individual answers.

Second, the ethnography of e-health that I offer focuses on one group of users: patients. This reflects a particular research interest in how patients experience and react to changing infrastructures and narratives of care. Moreover, the focus on patients is a result of the research position that the user test afforded me. More time and efforts had to be put into instructing the patient users who were less familiar with the system than the clinician users. Furthermore, patients simply had to produce more contents and,

thus, spend more time using the system than clinicians, requiring me as facilitator to be in closer contact with patients than with clinicians. Thus, the circumstances of my practical engagement in the field led to a strengthening of my focus on patients: I was to some degree 'captured' (Scott et al 1990) by their perspectives. I could have attempted to counter this 'capturing' by pushing for more interactions with clinicians; however, under the circumstances, this would most likely have been fruitless and potentially have hampered my collaboration with the clinicians, who already had little time for the user test. Instead, I tried to make use of my particular position in the field. I was able to closely follow how patients' navigate when presented with invitations to participate and in the healthcare system, in general, as "*mutual enrolment*" (Martin 1996:265) between me and the patient users took place: as I enrolled patients as users of P-Record, they enrolled me as an ally or a 'knot' in their infrastructure of care. I believe that this mutual enrolment has been analytically productive. However, it also leaves clinicians' perspectives on e-health and patient participation less unfolded and conceptualized and, thus, calling for more attention in future ethnographic interventions into e-health and patient participation.

Together, my different interventions constitute my overall answer to the invitation to participate as a social science researcher in the field of e-health. Whether directed at research, design, or practice/policy-making, my contributions require translations; and as I contribute to a specific as well as an overall e-health project with multiple agendas, it is ultimately impossible for me to control the proliferating effects of my interventions (to paraphrase Zuiderent-Jerak & Jensen 2007:231). I can only hope to inspire any actor in the field to critically reflect on the workings and implications on patient-involving e-health – that is, to bracket utopian as well as dystopian future patient imaginaries (Finch et al 2008; Pols 2012) and, instead, inquire into the practical and situated productivity of invitations to participate.

4.3 Conclusion: what patient-involving e-health is and can become

In sum, this thesis provides an ethnographic exploration of patient-involving e-health in heart care that highlights the particularities of practicing participation-by-invitation. It took as its starting point the common narrative of e-health as a vehicle for transforming healthcare towards more participatory practices, with multiple improved outcomes.

“eHealth holds the promise of revolutionizing health-care”, as, for instance, Meier et al (2013) writes, *“by improving its efficiency; extending and enhancing its reach; energizing and engaging its practitioners and their patients; and in the process, democratizing, decentralizing, and even partially demystifying the practice of medicine”* (p.376). Focusing on the user test of the e-health system, P-Record, I have treated this bold promise of e-health as both a matter of concern and a matter of fact.

Approaching the promise of e-health as a *concern*, I have explored the practical implications of introducing e-health as a tool to ‘engage’ patients as information providers, with the added connotations of ‘partners’ as well as ‘self-carers’. Providing information is no straight-forward task. In assessing what will constitute relevant information in a particular context of care, patients have to undertake a work of ‘filtering’ information that relies on experience, knowledge and anticipations of the outcomes. This may result in highly diverging sets of information and, not least, diverging expectations of response, which clinicians, on their side, have to filter and manage. E-health systems can be more or less supportive of this filtration work, and more or less biased towards one group of users. In the case of P-Record, I have demonstrated how the system especially failed to assist patients in their filtration work. This, however, also had implications for clinicians who were faced with inadequate or superfluous information and, in some cases, expectations they could not meet.

Hence, involving patients as information providers poses a number of challenges for patients as well as clinicians. Most notably, these challenges have to do with defining and negotiating relevance and responsibilities, but also with issues such as managing expectations and balancing compliance and respect for patients’ individual ways of coping with illness. These are challenges that patients and clinicians already face, e-health or not. However, something new happens when e-health is introduced and practices and roles thereby are opened up for reconfiguration and, not least, renegotiation. The often bold and comprehensive promises of participation and, in general, improvement of care practices that are vested in e-health are vivid actors in this renegotiation. As different patient imaginaries rally in the scripts in and surrounding e-health technologies, efforts to involve patients as first and foremost information providers are complicated by ambiguous tools and invitations. They become

complicated for patients, as this thesis most extensively demonstrates, but certainly also for clinicians.

Approaching the promise of e-health as a *fact*, I have contributed recommendations for e-health design that take into account the exposed implications of inviting patients to participate with e-health and, more basically, recognize the situated and unpredictable nature of any so-called ‘solution’, *without* entirely dismissing the ambition to design tools to help reconfigure care in a sustainable and desirable way. Firstly, a prerequisite for viable e-health design is an awareness of the multiple projects of patients and clinicians. On this backdrop, designing e-health becomes a matter of negotiating and, if possible, *aligning* these projects, while keeping in mind that ‘less may be more’. Inclusive invitations risk being *ambiguous* invitations, which set patients and clinicians to work in ways that create problematic overflows. Secondly, as projects are dynamic so must design be. This leaves designers with the challenge of how to support a continuous adjustment of expectations.

Meanwhile, this thesis suggests that introducing new e-health tools – whether they survive or not – provides a valuable opportunity for exploring, through experimenting, what e-health and patient participation is and, not least, what it may become. On the basis of the user test of the system *P-Record*, the thesis has offered a glimpse into the relations and dependencies that precede and arise from the use of tools to instigate patient participation. As an ethnographic exploration, the thesis provides a *situated* description of what kind of sociotechnical arrangement, patient-involving e-health in practice may comprise and which effects it may produce, whether intended or not. Rather than providing evaluative conclusions as to how well e-health delivers on the promised outcomes or identifying barriers and facilitators for successful design and implementation, it shows some of the dynamics between devices and users; promises and expectations; and individual and collective projects that are set in motion when e-health is introduced as a presumed ‘vehicle’ for participatory healthcare – for better and for worse.

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Appendix I: Information for research participants

Information for research participants: user test of P-Record.

København, d. 28. oktober 2012

Information til deltagere i forskningsprojekt: afprøvning af IT-værktøj til ICD-bærere

Er du ICD/pacemaker-bærer, og har du lyst til at være med til at afprøve et nyt patientrettet IT-værktøj?

Om IT-værktøjet:

EHealthbox er et kommunikationsredskab primært målrettet ICD-bærere. Det tilgås via Internettet og indeholder muligheden for, at patienten kan forberede sig til aftaler i klinikken (en fjernaflæsning, aflæsning ved fysisk fremmøde eller kontrol på Bispebjerg Hospital) ved at fortælle, hvordan man har haft det siden sidst og dele dette med klinikerne på forhånd. Desuden kan patienten skabe overblik over sin medicin, skrive dagbog over symptomer og events, dele sine erfaringer med andre ICD-bærere m.m..

Om deltagelse:

Som deltager vil du modtage instruktion i anvendelse af eHealthbox i dit hjem og skulle prøve at anvende eHealthbox i forbindelse med 1 fjernaflæsning og/eller 1 aflæsning ved fysisk fremmøde i Paceambulatoriet samt 1 kontrol på Bispebjerg Hospital. Efterfølgende vil vi gerne interviewe dig om dine oplevelser med at bruge eHealthbox. Det vil blive nødvendigt at aftale ekstraordinære kontroller på hhv. Rigshospitalet og Bispebjerg Hospital, hvis du ikke i forvejen har aftale om kontroller i projektperioden (november til december 2012).

Om forskningsprojektet:

EHealthbox er udviklet i et samarbejde mellem forskere, klinikere og en privat It-virksomhed, og afprøves i perioden november-december 2012 på Rigshospitalet og Bispebjerg Hospital. Afprøvningen er en del af et større forskningsprojekt (CITH-projektet), der har til formål at undersøge, hvordan IT kan bidrage til at involvere patienter og styrke kommunikationen mellem hjem og klinik, og konkret at udvikle IT til understøttelse af hjemmemonitorering af hjertepatienter. Afprøvningen varetages af ph.d.-studerende ved Københavns Universitet, Institut for Folkesundhedsvidenskab, Karen Dam Nielsen, i samarbejde med klinikere på Rigshospitalet og Bispebjerg Hospital.

Hvis du er interesseret i at deltage eller blot at høre mere om projektet, er du velkommen til at kontakte Karen Dam Nielsen på e-mail: kadn@sund.ku.dk eller telefon 21 16 16 38.



Du kan også læse mere på CITH-projektets hjemmeside:

<http://www.cith.dk/>

<http://www.cith.dk/people/karen/>



Information for research participants: additional fieldwork.

København, d. 28.marts 2012

Information til deltagere

Forskningsprojekt om selv- og hjemmemonitorering i hjertebehandling

Dette kvalitative forskningsprojekt undersøger, hvordan forskellige mobile teknologier – eller *hjemmemonitoreringsdevices* - bruges i udredning og behandling inden for hjerteområdet. Projektet undersøger dels, hvordan den information, som indsamles ved hjælp af de forskellige devices (primært til måling af EKG), patientdagbøger etc., bruges i arbejdet i klinikken, dels hvordan patienter oplever at indgå i hjemmemonitoreringsforløb af forskellig karakter og varighed. Projektet har overordnet fokus på, hvordan selv-/hjemmemonitorering påvirker kommunikation og samarbejde mellem hjem og klinik, og hvordan IT allerede indgår eller i fremtiden vil kunne indgå heri.

Projektet er del af et større forskningsprojekt (CITH-projektet), der har til formål at udvikle IT til understøttelse af hjemmemonitorering af hjertepatienter (konkret ICD-patienter), og udføres af undertegnede, ph.d.-studerende Karen Dam Nielsen.

Alle, der deltager (enten i interviews eller ved observationer i klinikken), indgår anonymt i projektet og vil ikke kunne genkendes i formidlingen af forskningsresultater.

Hvis du er interesseret i at høre mere om projektet, er du velkommen til at kontakte mig på e-mail: kadn@sund.ku.dk eller telefon 35 32 79 37.

Du kan også læse mere på CITH-projektets hjemmeside:

<http://www.cith.dk/>

<http://www.cith.dk/people/karen/>

Med venlig hilsen

Karen Dam Nielsen

Cand.comm., Ph.d.-studerende

Afdeling for Sundhedstjenesteforskning

Institut for Folkesundhedsvidenskab, Københavns Universitet



DET SUNDHEDSVIDENSKABELIGE FAKULTET
KØBENHAVNS UNIVERSITET



CITH

Co-constructing IT and Healthcare

Appendix II: Instruction for patient users

*Forskningsprojektet CITH: Afprøvning af et IT-værktøj til ICD-bærere. November-december 2012.
Rigshospitalet, Bispebjerg Hospital og Københavns Universitet*

Om brug af eHealthbox



At logge på:

Åbn Internet Explorer eller Firefox.

Skriv følgende i adressefeltet: icd.ehealthbox.dk/logica.com

Klik på [Start eHealthbox](#) (står til højre på siden og er markeret med blåt)

Indtast dit brugernavn: _____ og password: _____

Lidt om funktionerne:

Når du så er logget på, kan du klikke på det ikon, som du vil bruge. Et lille vindue åbner. Du kan godt have flere vinduer åbne samtidig. Indtast og gem information. Du kan når som helst rette i det, du har skrevet.



AFTALER

I "Aftaler" kan du skrive dine aftaler med hospitalet ind i en kalender.

I forbindelse med aftaler om fjernaflæsning og kontrolbesøg kan du så:



FORBEREDELSE



MEDICIN

- Udfylde en "Forberedelse" til den type aftale, du har (skal være udfyldt senest 24 timer før den pågældende aftale)
- Opdatere din medicinliste i "Medicin".



LOGBOG

Du kan derudover bruge "Logbog" til at:

- Skrive dagbog ("dagbogsnotat")
- Skrive om din "sygehistorie"
- Løbende notere de symptomer, du eventuelt oplever ("symptomnotat")



BESKEDER

Endelig du kan bruge "Beskeder" til at kontakte læger og bioanalytikere, eller testansvarlig Karen Dam Nielsen.



NETVÆRK

Du kan også skrive til andre patienter (testbrugere) eller kigge på deres forskellige notater (fx sygehistorie), hvis de har valgt at have en tilgængelig profil, som du kan se i "Netværk". Her kan du også dele din egen profil med andre patienter (testbrugere).

Instruction sheet, page 2.

*Forskningsprojektet CITH: Afprøvning af et IT-værktøj til ICD-bærere. November-december 2012.
Rigshospitalet, Bispebjerg Hospital og Københavns Universitet*

(vend)

OBS: Vigtigt om kontakt til hospitalet:

Hvis du sender en besked via eHealthbox til en læge eller bioanalytiker, så vær opmærksom på, at der kan gå lang tid, inden de læser den. Hvis du har akutte spørgsmål til din ICD eller medicinske behandling, så kontakt hospitalet pr. telefon, som du normalt ville gøre!

Spørgsmål og hjælp:

Har du spørgsmål til brug af eHealthbox, eller hvis systemet ikke fungerer, så kontakt Karen Dam Nielsen på tlf. 21 16 16 38 (dagtimer fra ca. kl. 10-17) eller skriv en besked i eHealthbox til Karen Dam Nielsen (administrator) eller på mail kadn@sund.ku.dk om, at du ønsker at blive kontaktet.

Appendix III: Screen shots from P-Record

Figure 1. Patient-user interface (test user profile) with five of the six features/‘widgets’ open. Translation of the Danish headlines: ‘Aftaler’ = Calendar, ‘Logbog’ = Logbook, ‘Beskeder’ = Messages, ‘Medicin’ = Medication, ‘Forberedelse’ = Preparation, ‘Netværk’ = Network.

The screenshot shows the eHealthBox interface for user 'cathlyn cathlyn, 010170-1234'. The top navigation bar includes icons for Aftaler, Logbog, Medicin, Forberedelse, Beskeder, and Netværk. Five widgets are open:

- Aftaler (Calendar):** A table of appointments with columns for Date, Appointment, and Type. It lists various consultations and hospital visits from 20-09-2012 to 03-09-2012.
- Logbog (Logbook):** A table of logbook entries with columns for Date, Entry, and Category. It shows entries for 24-09-2012 and 15-09-2012.
- Beskeder (Messages):** A list of messages with columns for Name, Date, and Status. It shows multiple messages from 'Henry Henry' dated 19-09-2012.
- Medicin (Medication):** A table of active medications with columns for Name, Dose, Date, and Order. It lists various medications like 'test endoste 9', 'test endoste 10', etc.
- Forberedelse (Preparation):** A table of preparation tasks with columns for Type, Date, and Time. It lists various preparation tasks like 'Forberedelse til ambulant besøg på Bispebjerg Hospital'.

Figure 2. Preparation form, first page: “Type of appointment”.

The screenshot shows the 'Forberedelse' (Preparation) form. The top section is titled 'Forberedelse' and has a 'Rediger forberedelse' button. Below this is a tabbed interface with tabs for 'Type', 'Alment', 'Siden sidst', 'Symptomer', and 'Spørgsmål'. The 'Type' tab is selected, showing a form for 'Forberedelse til' (Preparation for). The form includes a dropdown menu for 'Forberedelse Fjernaflysning' and a date/time selector set to '10-12-2012' and '21:00'. Below this, a message states: 'Forberedelsen skal være udfyldt senest d. 10-12-2012 21:00'. A yellow highlighted box contains the text: 'Forberedelsen mangler helt eller delvist at blive udfyldt'. At the bottom, there is a message: 'Du kan altid redigere i forberedelsen. Den lukkes dog 24 timer inden konsultation eller aflysning'. The bottom navigation bar includes buttons for 'Næste', 'Fortryd', 'Slet', 'Gem og fortsæt', 'Gem og afslut', and 'Luk'.

Figure 3. Preparation form, second page: “General wellbeing”. Question: “How have you been, in general ? (related to your health, as when your doctor asks you)”.

Forberedelse

Forberedelser Rediger forberedelse

Type Alment Siden sidst Symptomer Spørgsmål

Alment

Hvordan har du det helt overordnet? (Helbredsrelateret, ligesom når din læge spørger dig)

[Text input area]

Næste Fortryd Slet Gem og fortsæt Gem og afslut

Figure 4. Preparation form, third page: “Since last time”. Question: “How have you been since the last appointment? (use keywords and prioritize your answers)”.

Forberedelse

Forberedelser Rediger forberedelse

Type Alment Siden sidst Symptomer Spørgsmål

Siden sidst

Hvordan har du haft det siden sidst? (Brug stikord og prioriter dine svar)

1: [Text input]

2: [Text input]

3: [Text input]

4: [Text input]

5: [Text input]

Er din medicinliste opdateret? Vis

☐ Min medicinliste er helt opdateret

Næste Fortryd Slet Gem og fortsæt Gem og afslut

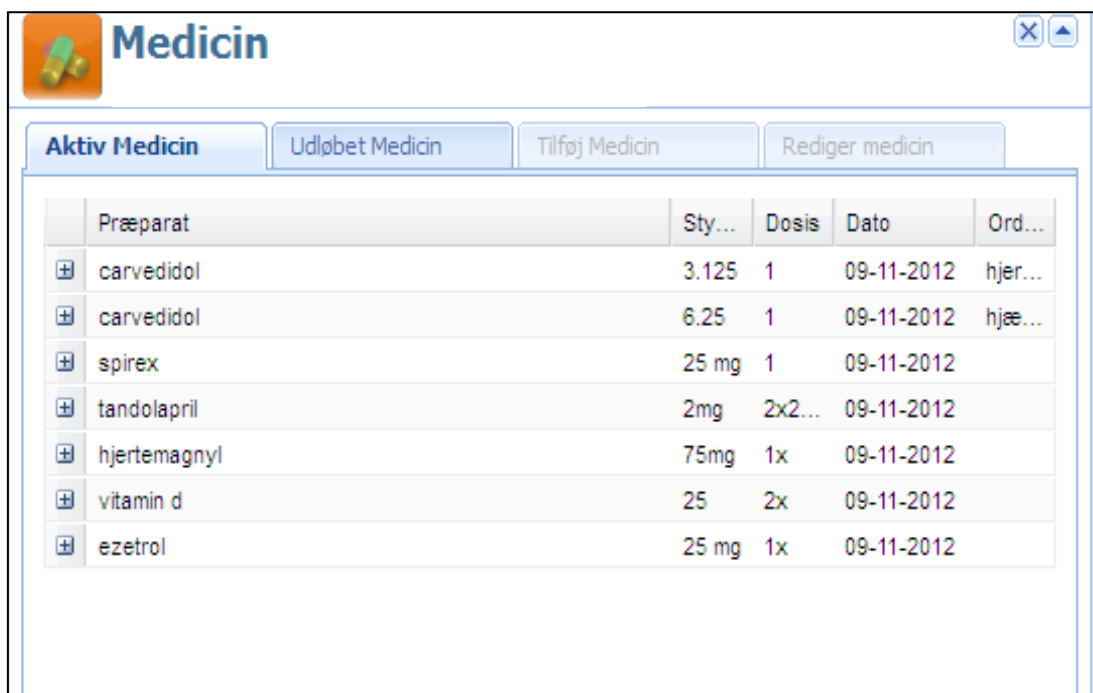
Figure 5. Preparation form, fourth page: “Symptoms”. Question: “Have you experienced any of these symptoms since last time?”

The screenshot shows a web application window titled 'Forberedelse'. It has a navigation bar with tabs: 'Forberedelser', 'Rediger forberedelse', 'Type', 'Alment', 'Siden sidst', 'Symptomer' (selected), and 'Spørgsmål'. The main content area is titled 'Symptomer' and contains the question: 'Har du oplevet nogle af disse symptomer siden sidst?'. Below the question is a list of symptoms, each with a checkbox: 'Lommeproblemer', 'Åndenød', 'Træthed', 'Hjertebanken', 'Svimmelhed', 'Nær besvimelse', 'Besvimelse', 'Hævede ben', and 'Kvalme'. At the bottom of the window, there are several buttons: 'Næste', 'Forrige', 'Slet', 'Gem og fortsæt', and 'Gem og afslut'.

Figure 6. Preparation form, fifth page: “Questions”. Question: “What would you like to talk about at the meeting? (use keywords and prioritize your answers)”.

The screenshot shows the same 'Forberedelse' web application window, but with the 'Spørgsmål' tab selected. The main content area is titled 'Spørgsmål' and contains the question: 'Hvad vil du gerne tale om til mødet? (Brug stikord og prioriter dine svar)'. Below the question are five numbered input fields (1: to 5:). At the bottom of the input fields, there is a checkbox with the text: 'Klik her, hvis du ikke mener at have behov for den planlagte konsultation på nuværende tidspunkt'. Below this checkbox is a paragraph of text: 'I givet fald bedes du telefonisk aflyse konsultationen og aftale et ambulatoriebesøg til et senere tidspunkt. Under alle omstændigheder bedes du gemme din forberedelse nu!'. At the bottom of the window, there are four buttons: 'Fortryd', 'Slet', 'Gem og fortsæt', and 'Gem og afslut'.

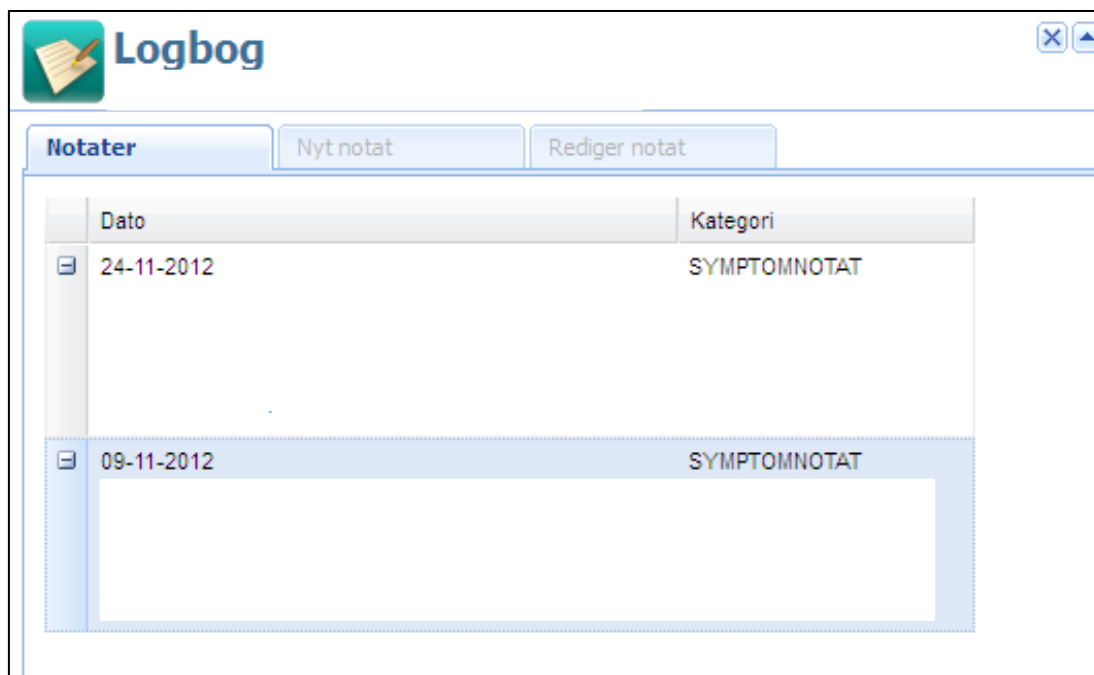
Figure 7. Medication list (example). Consisting of four pages: “Active medication”; “Expired medication”; “Add medication”; “Edit medication”.



The screenshot shows the 'Medicin' application window. It has a title bar with a close button and a maximize button. Below the title bar is a menu bar with four items: 'Aktiv Medicin' (selected), 'Udløbet Medicin', 'Tilføj Medicin', and 'Rediger medicin'. The main area displays a table of active medications.

	Præparat	Sty...	Dosis	Dato	Ord...
	carvedidol	3.125	1	09-11-2012	hjer...
	carvedidol	6.25	1	09-11-2012	hjæ...
	spirex	25 mg	1	09-11-2012	
	tandolapril	2mg	2x2...	09-11-2012	
	hjertermagnyl	75mg	1x	09-11-2012	
	vitamin d	25	2x	09-11-2012	
	ezetrol	25 mg	1x	09-11-2012	

Figure 8. Logbook (example). Consisting of four pages: “Notes”; “New note”; “Edit note”.



The screenshot shows the 'Logbog' application window. It has a title bar with a close button and a maximize button. Below the title bar is a menu bar with three items: 'Notater' (selected), 'Nyt notat', and 'Rediger notat'. The main area displays a list of notes.

	Dato	Kategori
	24-11-2012	SYMPTOMNOTAT
	09-11-2012	SYMPTOMNOTAT

PAPERS 1-4

Paper 1

Inviting information, inviting patients: participatory scopic devices in remote heart monitoring

Author: Karen Dam Nielsen

Publication status: Unpublished manuscript.

Abstract

When e-health is brought into chronic care, it is often with the overall intention of creating new pathways for information and care between home and clinic by involving patients. As such, e-health technologies can be understood as: 1) *scopic media* (Cetina 2009), which blur spatial and temporal borders between home and clinic by allowing information to travel, and furthermore, 2) *participatory devices* (Marres 2011), which enable patients to assist in the production and sharing of this information. With reference to exactly these capacities, e-health is widely heralded – or problematized – as fundamentally changing existing care practices. However, e-health can also be understood as following in close line with more mundane technologies that invite patients to become providers of contextual information and thus participants in their own care. In heart care, paper diaries and phone calls are examples of existing ways of enhancing the clinical scope and invite in patient-generated information that precede and coexist with e-health. Based on ethnographic fieldwork, this paper examines some of these existing technologies, with a focus on short-term heart monitoring. It describes their workings as ‘participatory scopic devices’ and subsequently argues that these technologies can provide a valuable glimpse into possible implications of patient-involving e-health, for instance the problem of defining relevant information and the overflows this creates. Furthermore, the paper suggests thinking of e-health technologies as continuations rather than revolutions of existing practices of inviting in information and patients.

Keywords: e-health; heart care; remote monitoring; patient-involvement; paper diaries; scopic media; participatory devices

Introduction

Transformation, fundamental disturbance, or even revolution – these are words often used to describe the effects of patient-involving e-health on healthcare ‘as we know it’ (e.g. Ball & Lillis 2001; Dedding et al 2011; Weiner 2012). The typical e-health narrative is one of novelty—of a symmetrical relation between technological innovation and discontinuation of existing practices. In related imaginaries of ‘the future e-patient’ (Felt et al 2009), it is thus assumed that patients will come to play *new* roles, e.g. as data and information producers and thereby collaborators in clinical analysis and decision-making processes. This anticipation seems plausible and, in any case, serves to flag important attention to the social and organizational implications of introducing new technology. Yet, e-health might not always represent radical change, but rather a continuation of well-established practices, only in materially new versions. This is also the case with e-health technologies that aim at making patients ‘active participants’ as *information providers*. While many of these technologies are still in their infancy and thus rather slippery study objects, we might therefore turn our attention

to their preceding and often more mundane versions and there look for lessons to be learned. What can these practices teach us about the social and organizational implications of inviting patients to provide information?

In heart care, the ‘remote’ provision of information by patients is both part of well-established practices and recent e-health visions. As many other clinical domains, heart care involves a continuous quest for ‘authentic data’ and a technically dense landscape of tools to obtain such data from the homes and everyday lives of patients, be it short-term monitoring devices for diagnostics or telemonitoring of pacemakers and implantable cardioverter defibrillators (ICD’s). In these practices, patient-generated contextual information is of great importance to clinicians’ work of processing the vast amounts of data obtained through monitoring devices. As a relatively new field and one in rapid growth and technical development, ICD-telemonitoring has been in the search for (e-health) tools to enable the incorporation of contextual information (e.g. Andersen 2011; Cowie et al 2013). Meanwhile, such tools have long been an integral part of short-term monitoring, only in much more ‘low-tech’ versions (most commonly in the form of paper diaries) and therefore perhaps not where e-health entrepreneurs would first think to look for inspiration. Moreover, the seemingly big differences between short-term monitoring and telemonitoring of pacemakers and ICDs regarding technical as well as clinical complexity may conceal similar capacities and implications related to patient-involvement – similarities from which we may learn and, moreover, similarities that make these otherwise different practices form a shared landscape, or layering, of technologies, also for the individual heart patients who travel through it during their illness trajectories.

In the light of the design and test of a specific e-health system for ICD-patients, P-Record, I set out to explore the ‘mundane’ practices of short-term heart monitoring at a Danish university hospital, focusing on the use of *paper diaries* to obtain contextual information from patients – a practice that in many ways resemble what P-Record was envisioned to do in ICD-care. To enable comparison and transfer of insights between the two different setups and their devices, I also propose a conceptualization that allows me to bring forth their shared capacities and implications, namely that of ‘*participatory scopic devices*’. Both short and long term heart monitoring work to enhance the scope of the clinic into the homes and everyday lives of patients (and their hearts) and can thus, following Cetina (2009), be understood as “*scopic arrangements*”. In these arrangements, the involved tools for obtaining both ‘authentic data’ outside the clinic and patient-provided ‘contextual information’ work as scopic media that help overcome the spatial and temporal delimitations of the clinical encounter. Heart care contains several “*scopic media*”, which often only require a minimum of action by patients. However, the scopic capacity of, for instance, 24-hour Holter-monitors is enhanced when adding to them technologies such as paper diaries, underscoring and supporting the participatory role of patients. That is, they more vividly work as ‘participatory devices’ (Marres 2011), first of all enabling patients to provide information, but also – importantly – allowing or even stimulating patients to acquire insights into their own condition and treatment, to bring forth concerns, and

take on a the role and responsibilities of producers rather than merely receivers of healthcare. The latter, extensive participatory capacity is often an explicit intention with e-health, while it might only be an unintended side-effect of paper diaries.

I suggest, that speaking of various tools – whether e-health or low tech – for enhancing and adjusting the informational flow in heart monitoring by involving patients as ‘participatory scopic devices’ allows us to see and address the common capacities and implications of these rather than presuming difference and novelty when new innovation-related terms appear, such as ‘e-health’. In other words, describing e-health and the many technologies that precede and coexist with it in terms of their capacities rather than technical properties, will bring forth an image of continuity rather than revolution, which may further spark us to see the value of studying the workings of existing technologies and learn from these when developing new technologies. Here, it allows me to explore the landscape that an e-health tool like P-record would feed into. How are ‘participatory scopic devices’ already being used here, and what can we learn from about core challenges of involving patients as information providers in heart care? The answers to these questions do not only have local value for e-health design in heart care, but also contribute to conceptualize and understand telemedical practices within an overall CSCW-framework (Computer Supported Cooperative Work), as called for by Fitzpatrick & Ellingsen (2012): How are ‘absent-yet-present patients’ involved in collaborative medical practices; how do they contribute; and, how should clinicians responds to them?

Conceptualizing devices for obtaining information in heart monitoring

The field of CSCW has long been invested in studying healthcare work as situated, collaborative, and increasingly computer-supported practices (for an overview, see Fitzgerald & Ellingsen 2012). While often departing from an ambition to help qualify the development and/or introduction of new computer systems and thereby being part of innovation-oriented ventures, CSCW-scholars have also stressed the importance of designing for *support* rather replacement of existing practices (Berg 1999). In practice, this will often mean striving to either supplement or mimic existing tools and practices when designing computer systems, and this inevitably requires in-depth knowledge of these. This prescriptive point rests on two descriptive claims that have been repeatedly substantiated within to CSCW. Firstly, when new devices are introduced, old ones do not necessarily disappear – an insight that for instance has been incisively captured in the expression ‘persistent paper’ by Dykstra et al (2009) who show how the vision of ‘paperless offices’ also still remains a myth in health care, despite decades of digitalization efforts. New technologies will therefore not enter an empty landscape, but instead must be integrated into complex and often technologically-dense environments, a situation that poses interoperability challenges of technical but perhaps especially social/organizational nature (Kaplan & Harris-Salamone 2009). Secondly, existing ‘low-tech’ practices and tools may have benefits as well as relevant implications that are easily overlooked by innovation-eager designers and decision-makers. However, numerous CSCW-studies of the coordination of work

and the artifacts involved have demonstrated the highly performative capacities of very mundane technologies and subsequently stressed the importance of '*tak(ing) the mundane seriously*' (Svensson et al 2007, 59) when designing ICT for complex work settings such as those in healthcare. Studies have for instance shown the intricate workings and sometimes even advantages of paper records (e.g. Heath & Luff 1996, Luff & Heath 1998), white boards (e.g. Bjørn & Hertzum 2011), medication forms (e.g. Bossen & Markussen 2010), and informal notes/working sheets (e.g. Østerlund 2007), demonstrating these artifacts as key 'ordering devices' (Bossen & Markussen 2010) in health care work.

In the case of remote heart monitoring and the associated ambitions to develop patient-involving e-health, paper diaries – and the short-term home monitors they accompany – constitute such mundane ordering devices that we may benefit from inquiring into. To do so, I suggest we need a vocabulary that allows for grasping their capacities beyond being intra-organizational ordering devices and regardless of their level of technical sophistication, that is, as monitoring devices embedded in a network of different low- and high-tech technologies and practices that together bridge the spatial and temporal divides between home and clinic. The technologies that I am interested in - technologies for obtaining patient-generated information, with paper diaries and e-health representing each end of the scale of technological complexity or 'novelty' - are supplements to other technologies in remote heart monitoring, so to speak, and treated as subordinate to these. They are part of a larger socio-technical arrangement that is put in place to enhance the clinical scope in diagnosing and treating heart disorders. Within this arrangement, they work to adjust the scope by rendering data meaningful in the light of context, and they do so by enabling the participation of patients as information providers. To describe this overall dual capacity of otherwise (seemingly) very different technologies, I first invoke the notion of 'scopic media' as tools that facilitate 'synthetic situations' (Cetina 2009), and then bring in the notion of 'participation devices' (Marres 2011).

Proposing the notion of 'participatory scopic devices'

The field of CSCW has adopted many of its core theoretical assumptions and concepts from symbolic interactionism, such as articulation work, ordering and boundary objects (e.g. Schmidt & Bannon 1992; Schmidt & Simone 1996; Star & Strauss 1999). Yet, Cetina's (2009) modification of Goffman's (1983) microsociology - centered around the notion of '*interaction order*' - has yet to receive widespread attention in CSCW, despite being exactly fitted for studying computer-mediated work practices. Primarily departing from studies of global financial markets, yet also illustrating her points with examples from medical work, Cetina proposes a conceptual framework to capture the specific qualities of '*global*' social interactions; that is, social activities taking place in '*synthetic situations*' as opposed to face-to-face encounters. ICT facilitates such 'non-physical/non-spatial' situations, Cetina suggests, defining the synthetic situation as "*an environment augmented (and temporalized) by fully or partially scoped components – in which we find ourselves in one another's and the scopic components*"

response presence, without needing to be in one another's physical presence" (Cetina 2009:69). While rarely global in a literal sense, remote heart monitoring in deed provides for synthetic situations: through different socio-technical arrangements, patients and clinicians collaborate across spatial (and temporal borders) in producing an 'image' of the state of a heart, a device, a life. In the process, they are, in some sense, 'present' to each other - although "*the accountability for responding*" (p.69) may exactly be a problematic issue, as I shall discuss later. In their capacity of facilitating synthetic situations, various remote heart monitoring arrangements thereby make up what Cetina calls '*scopic systems*', defining these as "*arrangement(s) of hardware, software, and human feeds that together function like a scope: like a mechanism of observation and projection*" (Cetina 2009:64). In the scopic system of short-term remote heart monitoring, for instance, the monitor, the computer and software, and the paper diary that the patient fill out constitute '*scopic media*' that work to scope the cardiac condition of the patient through '*the interplay of projection, contextualization, and responsiveness*' (Woermann 2012:627–referring to Cetina 2003, 2005).

Importantly, the scopic media of any remote heart monitoring arrangement only function when patients actively take part in the collaborative work of scoping – enabling '*the projection*' by handling the devices correctly and in providing '*the contextualization*' of the projection in the form of written, oral or, more indirectly, bodily information. To stress the importance of patients' role in the scopic system of remote heart monitoring, I add the adjective 'participatory' to the involved scopic devices that require or are explicitly meant to further patients' involvement. In coining these as 'participatory scopic devices', I am inspired by Marres and her analysis of '*material participation*' in environmental issues (2011, 2012). In this field, as well as in health care, several initiatives aim at enabling and instigating participation through devices, thereby embedding participation in material practices. In the field of remote heart monitoring, some technologies merely require and enable patient participation, like the paper diary, whereas others, like the before-mentioned e-health system P-Record, may also aim at furthering patient participation. In any case, I suggest that describing these technologies as participatory devices reminds us to zoom in on the role of the patient, and bring forth how the participatory capacities of the devices may both enable and complicate the collaborative work of 'scoping' in heart care.

Methods

The article is based on ethnographic fieldwork conducted at the heart center at a Danish university hospital that undertakes various forms of remote heart monitoring. The fieldwork was done between June 2011 and March 2013 as part of a three-year research project¹ that later

¹ CITH – Co-Constructing IT & Healthcare, see: www.cith.dk.

involved a user-test of an e-health service for ICD patients (P-Record). I conducted a total of four weeks of participant observation of different activities related to remote monitoring: instructing patients in how to use short-term monitoring devices, in-clinic follow-up for pacemaker and ICD patients, lab technicians' analysis of data from remote short term monitors, remote ICD follow-up's, ICD implantations, and consultations at the outpatient heart clinic after short-term remote monitoring. During observations, I had numerous informal conversations with both staff and patients about the practices of heart monitoring.

For background and additional descriptions, I draw on a selection of literature on remote heart monitoring cutting across the fields of cardiology, medical informatics, and sociology. Although far from being a systematic review, this hopefully enables me to sketch a local, yet widely recognizable, landscape of technologies and practices in remote heart monitoring.

The problem of context in long-term remote monitoring and the participatory vision

Before I engage with the so-called mundane devices of heart monitoring, the occasion for studying these should be elaborated on: the devices – existing and envisioned - that make others appear mundane. The specific point of departure for my inquiry into the broader landscape of remote heart monitoring is the user test of an e-health system for ICD-patients, P-Record, which among other things was designed to meet the challenges of obtaining contextual information from patients in relation to remote follow-ups of their ICD's: it was envisioned as a way of 'adjusting the scope' of remote monitoring by involving patients as information providers.

Since its introduction in the early year 2000's (Bjørn & Markussen 2013), ICD remote monitoring² has become widespread and widely heralded as a crucial innovation making ICD-care manageable; with a rapidly growing ICD-patient population, the workload of performing in-clinic follow-ups has generally become too heavy (Costa et al 2010). Without remote monitoring, patients have to visit specialized clinics approximately every three months to have the data stored by their ICD (about cardiac events, pacing/therapy, battery level, etc.) read and analyzed by clinicians – a time-consuming activity for everyone involved. Thus, the most acclaimed benefit of remote monitoring is a decreased number of follow-up visits, believed to

² ICD's are but one of several implantable cardiac devices increasingly being monitored remotely. Their technical properties and therapeutic capacities vary, with the ICD constituting the most advanced device, able provide shock-therapy when needed, and the Loop-recorder the most simple device, only monitoring the heart, for instance to follow a progressive heart disorder or after an invasive heart procedure (Camm 2014). While there are different clinical purposes and protocols linked to the different devices, and, importantly, different things at stake for their carriers, the remote monitoring practices around them are similar and often organizationally intertwined. Therefore, the issues I describe in relation to ICD remote monitoring are likely to have relevance for other long-term remote monitoring practices.

be time-saving for both patients and clinicians. Another benefit is early detection, which is believed to improve clinical outcomes and patient safety (Costa et al 2010; Ricci et al 2008). Nevertheless, claims of remote monitoring being cost-saving is increasingly brought into question, with several studies pointing out that evidence for the presumed efficiency of remote monitoring is in fact sparse, if not incomplete, and advocating more research into the clinical and organizational feasibility of remote monitoring (de Cock et al 2012; Afolabi & Kusumoto 2012).

At the heart of the matter are the large amounts of increasingly complex data that have to be interpreted and acted upon. Computer analysis and filtration of the data is an indispensable help as it reduces the amounts of data, turning these into actual '*information about patients without patient contact*' (Sinha et al 2006), but remote follow-ups are still a time-consuming and challenging task (Simmers 2012). One of the challenges is to interpret the incoming data in the absence of the patient. Often clinicians have to call patients to ask about symptoms and activities that may help them make sense of ambiguous data, deem an alert irrelevant, or give instructions. Thus, while remote monitoring may clearly substitute many in-clinic encounters, it also sparks numerous 'virtual encounters' conducted by phone (Simmers 2012). While some of these encounters may be perceived as inevitable and the only responsible thing to do, as in the case of serious alerts, others might be avoided by introducing other means of obtaining contextual information (ibid). In general, two different and, in principle, complementary solutions are suggested: better integration with existing sources of patient information (typically, the EPR) (e.g. Van der Velde et al 2012) or new tools for supporting patients in providing contextual information (e.g. Andersen et al 2011, Sahami Shirazi et al 2007). This brings us back to P-Record, which carries the vision of tapping into patients' potential for being 'diagnostic agents' as it has been demonstrated and conceptualized by Oudshoorn (2008, 2011) in relation to short-term heart monitoring. Although remote ICD-monitoring is often portrayed as valuable exactly because it does not require any active work from patients, and thus makes them independent of the clinical work 'behind the scenes', in effect, patients are dependent on and actively contribute to the infrastructure and practices of ICD-care (Bjørn & Markussen 2013). The 'scoping' of remote monitoring partly works because patients react to symptoms, maintain devices, and comply with the telemedical setup. Thus, in the logic of e-health design, patients constitute a valuable resource in the quest for contextualizing data. This would be a win-win solution: it would give clinicians the information they need to make sense of the 'raw' data, *and* patients would be supported in their self-care (Honey et al 2011; Andersen et al 2011). An e-health system like P-Record would both mend and enhance the clinical scope through patient-involvement. This is undoubtedly an innovation in ICD-care, and one that builds on novel technology. Yet, the *principle* is far from new – it is in fact central to the, in comparison, mundane and well-established practices of short-term monitoring, as I will demonstrate. So let us start from another beginning.

Hearts on screens: electrocardiography as scopic arrangement

The ability to record and visualize one of the most basic bodily features, the heart rhythm, has been around since the beginning of the 20th century where the electrocardiogram (ECG) was developed and first brought into clinical practice (Fisch 1989). A first line diagnostic tool (AlGhatrif & Lindsay 2012) as well as an almost iconic sign of vitality in popular culture, the ECG has become both a key and almost mundane medical technology. Over the years, a vast array of portable and implantable devices for in-clinic as well as remote heart monitoring has been developed and put into use. In cardiology, the ECG naturally plays a central role in diagnosing and treating heart disorders, not least various types of cardiac arrhythmias. ECGs are produced in-clinic at initial evaluations, as part of in-clinic physical stress tests, and increasingly *outside* the clinic in short or long-term remote monitoring. Indeed, since the early years, electrocardiography has involved delivering data over distance: ECG's were successfully transmitted by telephone wires as early as 1906 (Cowie et al 2013), the 1970's saw the introduction of transtelephonic pacemaker monitoring (Furman and Escher 1975), and since then, remote monitoring technologies have become an ever more integral part of heart care.

Much clinical work in this area, therefore, involves the display of ECGs on screens and interpreting these screen images, often without the patient being physically present. While first of all being a key marker of the condition of heart, the ECG can also be understood as depicting the very state of 'being alive', and more or less healthy. The ECG acts as a displaced manifestation of the body and life at stake, so to speak. It thereby works as a simple *scopic* element: the ECG basically widens the clinical scope by allowing the projection of the heart onto a screen. With the remote transmission of ECG's, the clinical scope is further enhanced, across spatial and temporal borders. We might say that remote monitoring enables a 'synthetic' clinical encounter to take place: the patient somehow becomes present in the clinic even when being physically absent.

Enhancing the scope with remote heart monitoring

Short-term remote monitoring has been part of clinical practice since the 1960's, where the portable ECG monitor (Holter-monitor) was introduced³. As in many other clinical domains, a central issue in detection and treatment of heart disorders is the quest for *authentic* data, which are often perceived as only obtainable outside of the clinic and over a longer period of time in the homes and everyday lives of the patient. Measuring a "real blood pressure" or detecting infrequent abnormal heart rhythms can best or even only be done by delegating the measurement practices to patients themselves outside the clinic. This is done as part of

³ Source: www.24h-monitoring.com.

diagnostics, treatment, as well as rehabilitation practices in heart care. In diagnostics, various devices are used for early evaluation of patients who present with heart symptoms; in treatment and rehabilitation devices are used to follow the betterment or worsening of a patient's condition (e.g. heart failure patients) to provide timely, clinical action (e.g. Chaundry et al 2011) and often also to facilitate self-care (e.g. Beatty et al 2013; Langstrup et al 2013). In practice, diagnostics, treatment, and rehabilitation may overlap, and different devices may be used for shifting or dual purposes⁴.

The most commonly used devices to detect cardiac arrhythmias are the before-mentioned Holter-monitor and different so-called event recorders. The Holter-monitor is carried around the neck or in a belt and attached by electrodes to the patient's chest. It monitors the heart rhythm continuously for typically 24-48 hours. In contrast, event recorders only record the heart rhythm when activated by the patient and then typically only for a few minutes or less, at a time. This also means that they can be used for longer periods. Some event recorders are fixed on patient's chests; others – like the 'event card' – are hand-held devices. In their abilities to enhance the clinical scope beyond the clinic, the various short-term monitoring devices and practices carry many similarities – with a few important differences related to the role of the patient as user. For sake of simplicity, I will focus my description of concrete practices of short-term monitoring on two devices: the Holter-device and the event card (figure 1). Serving as scopic media, both exhibit issues that apply to remote monitoring, in general, and together showcase what it takes to make these inherently synthetic situations work, with variations as to how 'authentic data' is obtained and filtered. For sake of simplicity, I will refer to them together as 'monitoring devices' when no distinction is needed.

Setting up the scope and getting authentic data

While short-term remote monitoring is used in many different clinical settings, including primary care, I base my analysis on the practices at a specialized heart clinic at a Danish university hospital. Here, the typical patient will be referred to the heart clinic's specially trained technicians by an in-house cardiologist as part of a diagnostic process where a heart rhythm disorder is suspected, due to symptomatic or genetic predictors, or simply to be ruled out. Often, the monitoring device is but one of many different diagnostic tools and tests employed, yet most of these are in-clinic, such as stress tests and ultra sound scans. During a brief encounter, the device is handed over to the patient by a technician with instructions for use. In the case of Holter-monitoring, the technician attaches the device by sticking electrodes

⁴ The landscape of available ECG monitoring devices is rapidly expanding, with new wireless and sensor-based technologies currently under development, also potentially widening clinical appropriation, for instance towards earlier, preventive detection, and increasing private/consumer appropriation (for examples and an overview of trends, see for instance Honeyman et al 2014; Higgins 2013; Baig et al 2013).

on to the patient's chest, turns on the device, and tells the patient that it will now monitor the heart for 24-48 hours. The patient is then briefly instructed in how to change the electrodes after showering and how to fill out a one-sheet paper diary "*if anything occurs*", as they often put it, and is finally asked to sign for the device and mail it back after two days. During instructions, technicians also ask patients to "*just do what they normally do*", underscoring that "*the doctors say that it has to be a natural everyday life*", the whole point of monitoring being to obtain data from the everyday situations where heart symptoms may occur and ideally identify the triggers. I will return to this moment of instruction, when describing the role of the paper diaries in a later section. In the case of event cards, instructions have an extra element: since patients have to activate the device themselves, they need to know how and, importantly, know when, as also described by Oudshoorn (2008). However, as the following situation illustrates, this 'know-now' (Pols 2012) receives less attention during instructions than the 'know-how' of using the card:

Sara (technician) calls in the next patient and, without much further due, shows her the event card. 'This side has to face the heart and be placed on the skin. It can record 30 seconds three times. After that you call us and then tell your name and CPR-number⁵ to the machine. Then we'll call you back and you can play the card to us and then there's room to record three more times. Sara asks the patient to unbutton her shirt a bit. "But maybe I won't have time (to record it) if an event is coming", the patient says. "No, that's the challenge with these cards", Sara replies, "but it is nice not having the wires, right." On Sara's request, the patient tries to make a recording while standing in front of the mirror, but the result is only a loud howling sound. Sara finds another card – this time it works: the sound is still loud, but has variations, and an ECG appears on the computer screen when Sara holds the card close to a connected microphone while we all keep as quit as possible. Sara again explains the procedure with calling in with the data and how to deliver the card back by either mail or leaving it at the reception. "So you simple have to hear that sound?" the patient asks. "Yes, you have to be able to hear the heart – duk duk duk", Sara says, "and it is very important that you make a note in the diary every time you press (the button). Otherwise call us, if you have any questions, as long as you don't play the card to the machine". "Yes, yes", the patient says with a smile. "Now, I am not so nervous, I've tried it before, you know, but if you haven't, then you might well be nervous." (Fieldnote, 15.03.2012)

With the event card, the patient thus has a crucial responsibility for making the core scopic elements – the card and the transferal of data via phone – work as well as securing the relevance of the data feeding the scope. This requires, besides technical skills, an ability to feel, interpret and act on symptoms – to do a kind of diagnostic work (Oudshoorn 2008). This can be perceived as a disadvantage as it introduces serious 'compliance issues' (Schreiber et al 2014; Sivikumar et al 2013) or as a benefit in that it may further patients' body awareness and self-care (Rubel et al 2005). Regardless, as participatory devices event cards make patients more directly involved in the production of 'authentic data' than Holter-monitors that only make patients responsible for providing the best conditions for, but not actively initiating, the production of data. However, this does not mean that the obtainment of 'authentic' data is less of a concern for patients; considering what constitutes good and sufficient data, patients often

⁵ Civil registration number/social security number.

ask technicians about how they should behave while carrying the monitor (should they wear it during sleep, can they shower, are sports off the limit, and what about attending a Christmas party?), or they may keep the device longer than agreed upon to be sure to capture an event. The enhanced scope is also a chance for patients to document otherwise elusive symptoms.



Figure 1. Left, a Holter-monitor with extra patches ready to be handed over to a patient. Right, an event card (Copyright by <http://cardiologyforless.com/image.php?type=P&id=1541>).

Dealing with the informational flow: on data plentitude – and deficit

When the remote monitoring device is returned to the clinic – or, in the case of event cards, when recordings have been transmitted by phone – technicians use a software system that translates the recordings into graphs and flags attention to what is perceived as irregularities or abnormal rhythms. The process of initial digital analysis and subsequent human analysis is common for Holter-monitors, event cards, and other heart monitors. Computer analysis of ECG's appeared in 1960's and 1970's (Macfarlane 1990) and, like in ICD-care, has generally made it possible to process larger amounts of data and save time (Salerno et al 2003). Furthermore, by reducing some of the complexities in the data and flagging attention to specific sequences, computer analysis works as a form of clinical decision-support, also allowing health professionals other than physicians and cardiologists to be enrolled in the interpretation of ECG's. While computer analysis has been criticized for producing inadequate or incorrect interpretations as well as leading to physicians losing their ability to interpret ECG's (Fisch 1989), it is by now an indispensable and constantly evolving part of the scopic arrangement of remote heart monitoring that make the informational flow just a little more manageable.

At the heart clinic, specially trained lab technicians do the subsequent 'human' analysis of the data by going through the graphs and highlights. When doing their analysis, the technicians will start by looking at the highlights and judge whether or not they are something to make a print of for the cardiologist. In this process of assessing clinical relevance and importance of the data, the technicians draw on multiple sources of information and skills: the indication written by the cardiologist in the referral letter, the paper diary, formal training and knowledge about heart rhythms, more tacit experience-based skills, and collegial advice. In addition to going over the highlights, technicians use the paper diary for capturing any events that the system might not

have highlighted – events, where the patient “*has felt something*”. Analysis can seem like a routine job, conducted in between patient visits, phone calls, and other tasks and even while listening to music and chatting with colleagues, the ‘ease’ of the process contributing to making the process rather intangible for the observer as well as hard to describe for the technicians themselves:

I am watching Sara conduct a Holter analysis while she tries to explain her process to me. “In the referral letter the doctors often note what we should be aware of, for instance VES (a specific type of extra heart beats) or palpitations, and that’s a big help”, she says, adding that the system also helps her by color highlighting what it believes to be events. However, sometimes it is wrong. Right now she is looking at an image of a lot VES’s—there are much more extra heart beats than “what normal people have”. “Maybe they can regulate it with medication” she says, while keeping her eyes on the screen. “If they were completely regular throughout 24 hours, it could also indicate that the patient has a pacemaker - pacemaker beats look like VES’s. But the doctor did not tick off that box (in the referral letter). Well, sometimes they just forget”. Sara further explains to me how the system also indicates names of the types of events it believes to be observing. Sometimes the system thinks that something is an event, but then it is only ‘noise’ - she “can just tell the difference”. While we have been talking, Sara has finished looking through the graphs and made prints of the relevant events. She fills out a summary form, attaches the prints, and places the report on top of the pile of remote monitoring reports ready to be handed over to the referring cardiologists. (Fieldnote, 15.03.2012)

Sometimes analysis is less straightforward, as in the following case. Here it becomes clear that technicians’ work of processing data is not only about knowing what is relevant when feeding the next level in the scope, but also about knowing when to take action.

Since this morning, Sara has been dealing with a very special case: the arrhythmia is abnormal, but completely regular. The patient has not noted anything in the diary. She prints a section of the graph – it looks like the pattern of a tightly knitted fabric. The analysis takes time and Sara goes over it an extra time to make sure she has not missed anything. She started the analysis yesterday, where she initially was very concerned. “My pulse jumped when I saw it”, she says and explains how she quickly called a doctor. “The doctor came and said ‘easy now’. It was looking quite normal for this type of patient, who is part of (name of research study)”. Sara explains that she does not know what the study is about, and why this patient is part of it, but it has been running ever since she joined the clinic. She often does not know the particular context that her analysis is part of, not to mention what is still waiting on her desk. “It’s really unpleasant to think about what might be there in the pile of recordings I haven’t yet attended to”, she says. “The recordings sometimes lie there for a long time before we get the analysis done, and there might be something acute, for instance someone who should have a pacemaker as soon as possible.” (Fieldnote, 30.03.2012)

What Sara and the other technicians are dealing with during analysis is a kind of synthetic situation. In this situation (figure 2), the monitoring device, the computer system, the screen, the paper diary, and the referral letter all work as *scopic elements* in that they “(enable) *translocal imports from the outer world to be collected, projected and augmented on-screen*” (Cetina 2009:69). As a scopic system, remote monitoring basically makes a heart visible, that is, the electrical system of the heart and a potential life-threatening arrhythmia. We might even say that what is projected on the screen in the clinic is basically the state of being alive or, as in the everyday parlance of the technicians’, the scopic system makes visible—and thereby in some sense *present*—‘the patient’. As Bjørn & Markussen (2013) also note in relation to ICD-monitoring: “*the object created during monitoring of the illness is not simply data as provided*

by the technology device. Instead, the object of concern during medical monitoring practices includes the patient in mind and body, a cyborg heart, with all its complexities.” (p.26). This co-presence of the patient-as-data and patient-as-body has also been captured in the notion of ICD-patients and their ‘data doubles’ by Grew & Svendsen (n.d.). In the situation above, Sara vividly reacts to an ‘embodied patient’ behind the otherwise foregrounded data (Grew & Svendssen n.d.), wondering if what is visualized in front of her is a life at risk. Without the patient actually there to provide her with ‘personal affective input and evidence’ (Bjørn & Markussen 2013:25—referring to Star 1991), and with Sara knowing very little about the medical context, she cannot determine the condition of this absent-yet-present patient whom she feels responsible for reacting on. Remote monitoring has enabled a *plentitude* of data to flow into the clinic, enhancing the clinical scope but thereby also the responsibility for reacting to the bodies within it. Yet, making sense of data—to know which are relevant and to know when to (re)act—itself relies on (other) data/information.

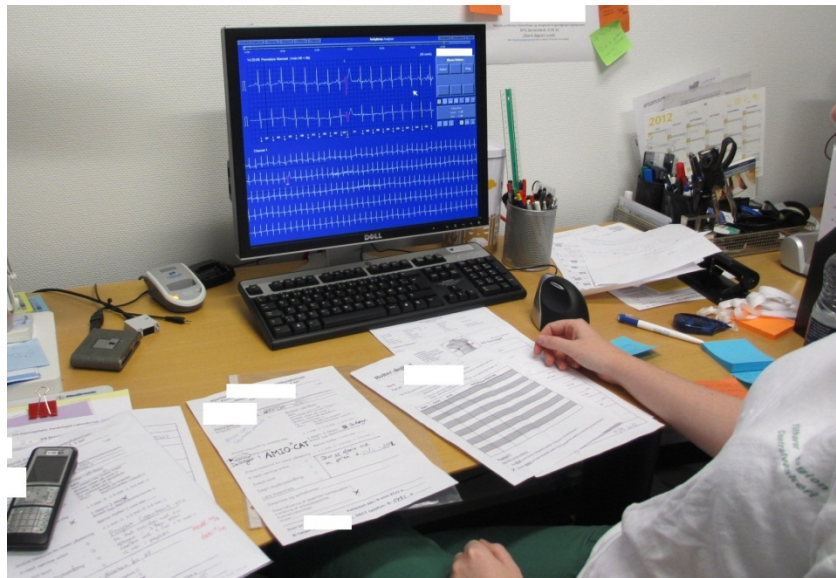


Figure 2. A technician doing Holter-analysis, with the different papers and the screen working together as scopic media.

Adjusting the scope: adding tools for contextualization

As hinted at above, the paper diary is meant as a tool to obtain this contextual information that can help technicians (and, later on, cardiologists) single out and interpret possibly relevant data sequences. In principle, the paper diary thereby constitutes an important scopic component in remote monitoring. With the paper diary, patients take part in adjusting the scope, provided that the contextual information they provide is itself relevant. Importantly, the diary may feed the scope in other, unintended ways.

The art of contextualization: what constitutes relevant information?

The paper diary (figure 3) is a one-sheet paper with an illustration of where to place the wires, instructive texts, and a table of four columns: 'date', 'from (time)', 'to (time)', and 'symptoms/activities', the latter with space for no more than a few words in typically sized hand-writing.

AMIO-CAT
Holter-dagbog

(contact details for the clinic - concealed for anonymity)

Navn : _____
Cpr.nr. : _____

a) Når De har denne Holter-optager på, bedes De udfylde nedenstående skema:

- 1) Hvis De får anfald af symptomer på hjerterytmeforstyrrelser, så beskriv arten og tidspunktet herfor.
- 2) Hvis De *anstrenger* Dem, f.eks. løber, cykler osv., hvor pulsen øges meget, så beskriv aktiviteten og tidspunktet.

Dato	fra kl.	til kl.	Symptomer/Aktivitet

b) **Vigtigt!!!**
Sæt kun 1 kryds nedenfor:
☐ Jeg **HAR** under Holter-optagelsen mærket symptomer på atrieflimmer.
☐ Jeg har **IKKE** på noget tidspunkt under Holter-optagelsen mærket symptomer på atrieflimmer.

Figure 3: The paper diary for Holter-monitoring. Translation of instructive texts:

- a)
- “When you are wearing this Holter-monitor, you are asked to fill out the form below:
- 1) If you have attacks of symptoms of heart rhythm disturbance, then describe the character and time.
 - 2) If you exert yourself, e.g. run, cycle, etc., where the pulse is significantly increased, then describe the activity and time.”
- b)
- “Important!!!!
Only tick one box below.
I HAVE experienced symptoms of atrium fibrillation during the Holter-monitoring.
I have NOT at any time experienced symptoms of atrium fibrillation during the Holter-monitoring.”

When technicians give instructions during the hand-out of monitoring devices, the importance of the diary is often stressed and the instructive text on the form repeated, yet neither technicians nor patients tend to dwell on what to write:

Jane has instructed the patient in how to use the monitor. “And now comes the important part”, she says, “and that’s this diary. Here (on top of the page) you can see how the wires should be attached”. “I have tried a completely different system before”, the patient chips in, while Jane continues explaining the diary: “Here you have to note down if you feel unwell, symptoms related to the heart and then if you do something that makes the pulse rise. We look through the whole recording no matter what. If there’s nothing to note, if you don’t experience anything out of the ordinary, then you tick this box”. Jane demonstrates the clock on the monitor and the patient asks detailed questions about how to handle the device. Jane explains and says: “You can’t really do anything wrong”. “Well, easy for you to say”, the patient says with a smile. “As long as you remember the things regarding the diary and how to attach the wires, then you can’t do anything wrong”, Jane says. “If you say so”, the patient sighs. (Fieldnote, 30.03.2012)

Instruction work is crucial in order to facilitate monitoring and thus ensure the functioning of the scope (see also Oudshoorn 2008; Langstrup & Winthereik 2010), and technicians are aware of the importance of providing instruction in all elements: the device, the wires, extra patches, the envelope for returning the device, and the paper diary. Patients also seem to recognize their responsibility for making the scope work; yet, during instruction the ‘hard elements’ - especially how to handle the device correctly - take center stage. Shaping relevant information may seem less crucial or, simply, less complicated. However, as the diversity in the returned diaries shows, this task is in fact riddled with interpretive flexibility (Pinch & Bijker 1984), which in result provides for very different resources in the clinicians’ interpretive work. In the following, I will give some examples of patients’ diverse uses of the diary.

Some diaries are simply returned blank. In case patients have ticked the box with ‘have NOT at any time experienced symptoms’ (see figure 3), a blank diary is no problem. But if no box is ticked, technicians basically do not know if the patient has not felt any or just forgotten to write about it, which causes some uncertainty, likewise in cases where no diary is returned at all. A lot of diaries are returned with only a few brief notes, like *‘running’*, *‘cycled from work and picked up the kids’*, *‘palpitation while resting’*, *‘played badminton’*, *‘took it off while showering’*, *‘jabbing in the chest and a lot of palpitation - watched TV on the couch’*, *‘chest pain + jump’*, *‘prickling, just so that I sensed it’*, *‘shortness of breath - ran/walked from 1th to 6th floor’*, *‘cycled in headwind, got a little short of breath’*, *‘on my way to bed, felt a little unwell’*. While seemingly in keeping with the layout of the diary and the instruction to note ‘attacks of symptoms of heart rhythm disturbance’ and exercise ‘where the pulse is significantly increased’ (see figure 3), these notes also show some of the ambiguities and ‘overflows’ that are related to the diaries. Firstly, describing a symptom - capturing the sensation and the grade - is challenging and can be done in many ways and in more or less everyday parlance. Importantly, a challenge also lies in identifying the symptom as related to the heart in the first place. Secondly, when patients describe activities, even very briefly, details about the everyday and personal lives of patients make their way into the scope, both through the seemingly clinical relevant information, such as *‘cycled’*, and the less obviously clinical relevant information like *‘picked up the kids’*.

More ‘outside the box’-use of the diary, both literally and in the sense of genre, exhibit further ambiguities and overflows. Some patients directly address clinicians (although mostly unspecified clinicians), referring to either previous or future encounters. An example is this patient who in a note below the table writes: *‘Ps. The patches did not cause itching or a red rash this time ☺’* – a note that may inform future clinical practices, and in any case refers to and perhaps nurtures an existing relation with clinicians. Other examples are making drawings of a malfunctioning device, elaborating on symptoms and activities on the back of the paper, and even reinventing the diary by attaching a printed version written on computer. Literally these notes do not fit into the box, in some cases seemingly because patients cannot sufficiently convey what they regard as relevant information in short phrases or keywords or simply because

they experience far more symptoms than what fits into the table. Patients may also explicitly challenge the diary format, like this patient who has chosen to write a long prose on a separate piece of paper and starts by stating that she is *'not really sure about this thing with the diary since I don't really do anything beyond the daily chores. I don't run and do not exercise'* and that the only thing she *'can think of'* is having visited a friend on the second floor using the stairs and raking leaves in the garden. She then thoroughly describes her general symptoms of not being able to *'run or even walk fast'*, how she *'feels as if the oxygen supply to the brain stops'*, and how she manages by having learned *'to stop in time'*. Finally she ends by expressing *'hope that something can be done'* and signs with a *'kind regards'*. For the technicians, a diary like this is hard to manage in that they have to do more work to extract from it what is relevant for their data analysis and furthermore find little use of information that cannot be correlated with a certain point in time and thus a particular data sequence. It simply does not provide the kind of context they need – the diary may enhance the scope, but not adjust it.

Cetina notes how, in order to ensure that the scope in the synthetic situation makes up a delimited and strictly relevant context, what she terms *'internal contextualization'* (Cetina 2009:66), participants must provide information of *relevance* and a certain *quality*. In short-term remote monitoring, the relevance and quality of the contextualizing information offered by the patient in the diary is a tricky and contested issue. The returned diaries reveal how providing relevant information is an ambiguous task, and, subsequently, what patients write is often either too little, too much, or simply irrelevant from the technicians' perspective. However, despite technicians' general complaints about the quality of the diaries, they do seem to gain information all the same. A blank diary tells them that perhaps they have not given sufficient instruction. A long narrative about spare time activities can spark recognition or make the patient a person they remember in future encounters. In any case, the diary is a reminder of the person behind the data. Thus, the diary *always* works as a scoping component: it does provide context, although it might not at first glance be assessed as a *relevant* context and thereby it falls outside of the *intended* scope of the situation.

Relevance across professional divides

The diaries are not just used by technicians in their processing of data for the cardiologist, but are also forwarded to cardiologist along with the report. The report consists of a summary form, prints of any relevant data sequences (identified either by indication from the system or from the diary), and the patient diary. The cardiologists will browse through the diary and compare it with the printed ECG sequences before or during an encounter with the patient in question and in some cases briefly refer to it while inquiring deeper into the patient's experiences or to explain their interpretation of the ECG. However, in general the diaries play no major role during encounters, nor do they completely fulfill their potential from the cardiologists' perspective.

At the outpatient heart clinic, I am sitting in on Henrik's (cardiologist) consultations. He briefs me about the next patient while looking through her Holter-report. She's an 18-year-old young girl with ischemic heart disease in the family. In the summery form, the technicians have noted "only activities in the diary". I ask him if he uses the diary. "I look", he says and pauses. "But I don't know how they (the technicians) instruct them in what to write in them. Do you know?" he asks me. "Well, briefly", I answer and ask if they are not useful to him. "Well..." Henrik says and shrugs his shoulders. He reads out loud from the diary: "Palpitation, was about to have a blood test done, was very nervous, afraid of needles; rapid heart rhythm, ran to the bus; rapid pulse, ran up fast up a hill." Henrik looks up: "Well, that's no wonder" (Fieldnote, 21.03.2013)

As a tool intended to work at different stages in the monitoring process for different professionals, the diary brings forth, and is caught up in, divergent professional logics and related perceptions of what constitutes relevant information. As one technician says when commenting on the diaries, in which patients in her opinion often write way too much: *"They are only supposed to write about experiences related to their heart rhythm, as it also says on the diary, but they write about all kinds of activities - I watched TV, I had coffee at this and that time, and so on"*. In contrast, one cardiologist generally thinks the diaries are very useful and important although *"people in general write too little – rather too much than too little"*. However, as the attitude of the cardiologist, Henrik, illustrates (fieldnote above), perceiving the diaries as giving 'too little or too much' information is not about the sheer quantity but rather the usefulness of information; in their respective processes of interpreting data, technicians and cardiologists may focus on different things and thus find different kinds of information useful. Technicians may for instance focus on identifying severe cardiac events and sometimes disregard more subtle events and patterns as 'noise' due to being primarily trained in monitoring pacemakers, as one cardiologist explains the different foci of technicians and cardiologists, as he experiences it.

Adding the different ways patients use the diary to the differences between cardiologists and technicians paints an image of multiple perceptions of relevance between all actors involved. This multiplicity may inhibit the internal contextualization otherwise strived for with the diaries and pose challenges to both the users and producers of information, but it also produces tacit, relational knowledge that makes the scope more than a 'pure information flow'.

Lessons learned about participatory scopic devices in remote heart monitoring

While the scopic system of short-term heart monitoring may be regarded as mundane - even too mundane to study, as one cardiologist pointed out when I started my fieldwork - making the scope work involves a number of challenges and overflows related to ensuring the right information flow that have to be managed by clinicians as well as patients. It all starts with the quest for authentic data, which brings devices out into the everyday lives of patients who then become responsible for providing good conditions for the data-collection. Enhancing the

clinical scope into the everyday lives of patients, however, leads to a simultaneous data overload and information deficit, and patients are further enrolled in making the scopic system work. The data *overload* is primarily managed by a socio-technical filtration in the clinic where data is processed and sorted by computers, technicians, and later cardiologists. The information *deficit* – the lack of context – emerges from this analytical process of making sense and use of the raw data, and to obtain contextual information, patients are then equipped with a paper diary. However, the diary entails more sorting and assessing, deficit and overload of information, thus constituting both a solution and a problem.

Put shortly, the case of short-term heart monitoring and its participatory scopic devices shows how patient participation can be a necessary but inherently problematic element of medical scoping, entrenched in the ongoing challenge of acquiring authentic and relevant data. Here, I will draw out two interlinked implications that arise from the challenge of ensuring internal contextualization, namely how to *define relevant information* and how to *manage the responsibilities* of providing and receiving this in a remote setup. I discuss how these implications may have broader relevance for e-health equivalents to the diaries, such as the system P-Record for ICD-patients.

How to define what is relevant information

Together with data from the monitoring device, the paper diary travels across institutional borders, facilitating and undergoing what Paul & Reddy (2010) have called an inter-service ‘sense-making trajectory’. But where the ECG-data are transformed - or translated - between each place of profession (Winthereik & Vikkelsø 2005), the diary is transmitted unchanged. It has to fit each place, although the professionals – technicians and cardiologists – have different tasks and different information needs. This makes it unlikely that the information in the diary will be relevant for both parties. Moreover, while the division of work between different professionals and places entails a step-by-step filtration of the data and thereby contributes to making data manageable, it also makes it unclear to patients who they are providing with information and, in some cases, directly addressing – with a smiley and a note about no allergic reaction or a detailed illness story and plea for medical help, as in the examples given earlier. To put it short, in a scopic system like heart monitoring, divisions of work both order and complicate the information flow. So do, in return, the multiple interpretations and ‘styles’ among patients regarding what constitutes relevant context.

The quest for authentic data and relevant contextual information in remote ICD-care overall resembles that of short-term heart monitoring; the two scopic arrangements further share the characteristic of involving a distributed, heterogeneous clinical collective through which the information generated in the home and by patients must travel and be (made) useful. Consequently, the described challenges of obtaining/providing relevant information are likely to apply to a situation where ICD-patients are equipped with a participatory scopic device like P-

Record. Ideally, an e-health system like P-Record could then be deliberately designed to assist patients in assessing relevance according to what would constitute clinically useful (internal) contextualization of the device data for different clinicians. Regardless if this is attempted and achieved or not, e-health brings a changed materiality to patient participation that can be said to provide more narrow limits for participation. With a paper diary, one can write outside the box, on the back, and in any style, and attach additional documents or even objects, such as a box of chocolate with words of gratitude, as I encountered during my fieldwork. With a device like P-Record, the format, extent, and even choice of words are delimited by the design, thus making it a device that furthers a more restricted form of participation than for instance paper diaries. In other words, ‘high-tech’ participatory scopic devices *in theory* have the potential to *improve* internal contextualization (to improve scoping), yet – in order to reach this end - may not per se facilitate *increased* patient participation (a common promise of e-health), but rather more restricted participation compared to low-tech devices.

Responsibilities involved in providing (and receiving) information

Ensuring internal contextualization through patient participation also involves responsibility issues for patients as well as clinicians that seem to be amplified by the heart of the matter, literally speaking, namely a potential life-threatening cardiac disorder. While the patient sometimes “*may become a relatively inactive, and at times immobilized, live attachment*” (Cetina 2009:70) in the technically and information dense scope of heart monitoring, participatory scopic elements like the monitoring device and the diary mean that “*(t)he quality of the information may become a moral responsibility*” for patients (p.70). Some patients seem to take this responsibility very seriously. They seem concerned with how to handle the device, how to behave while being monitored, and how to account for activities and symptoms that can be hard to describe. Sometimes the results are meticulous and creative writings, sometimes very sparse writings. Irrespectively, all patients write from the same basic condition, namely that they for a short while have been explicitly delegated part of the responsibility for detecting possible signs of a disorder that in the worst case may be fatal if left untreated or lead to a diagnosis that may hugely impact their lives. As in any diagnostic process, participation in the scoping of hearts is basically “*an engagement in which a future outcome becomes linked to a present commitment*” (Cetina 2009:80), yet in this case a future outcome of vivid “*fatefulness*” (ibid: 81). Some might feel anxious about this responsibility; others might not. Surely, it is outside the scope of this ethnography to draw conclusions as to what considerations patients go through when filling out the diary and thus the rationales behind the different results. Yet, it seems fair to assume that the otherwise different writings of patients all reflect attempts to handle the responsibility they have been given for feeding the scope in a situation with potentially a lot at stake (as also described by Oudshoorn 2008). Only patients do so based on individual ways of experiencing, making sense of, and verbalizing their ‘cardiac bodies’.

For ICD-patients, the fatefulness of the scope is even more concrete, as they have already suffered a heart attack or been diagnosed with a cardiac disorder that puts them at risk. Despite receiving ‘an extra life insurance’, as the ICD is often called, ICD-patients may still feel anxious and insecure about the technical setup. In this light, being ascribed more active roles in the scoping of their (and their device’s) condition with a participatory device like P-Record may be perceived as a welcomed chance to enhance the scope. Yet, it may also be perceived as a challenging burden or even a reminder of the deficiency of the otherwise ‘life-insuring’ scope of remote ICD-monitoring. In any case, just like patients equipped with Holter-monitors and paper diaries, ICD-patients equipped with e-health can be expected to experience and, importantly, interpret their responsibility for feeding the scope in multiple ways that far from always match the needs and expectations of clinicians.

As receivers of patient-generated information in a scopic system where patients are absent-yet-present, clinicians are also faced with responsibility issues, most evidently in the form of knowing when and how to respond – to the device data and to the contextual information. Cetina highlights what Goffman has termed ‘*response presence*’ (Goffman 1983:2) as both a precondition and a problem for coordinated action in a scopic system. In Cetina’s version, response presence describes the circumstance that “*the interacting party is not or need not be physically present but is accountable for responding without inappropriate delay to an incoming attention or interactional request*” (Cetina 2009:74). In heart monitoring, responding, first of all, means *taking action*. This responsibility lies at the heart of the technicians’ (and later the cardiologists’) analytical work and, for instance, is enacted through consulting colleagues about alarming observations, calling in patients, and, for cardiologists, initiating treatment upon diagnosis. Secondly, responsibility for responding can also be understood as responsibility for *answering*. In short-term heart monitoring, technicians particularly face the challenge of response presence in relation to knowing when to react on device data. The paper diaries are clearly framed as background information, yet some patients write in a way that indicates that they expect a direct answer to their writings, e.g. by posing questions. Actually answering such writings can then be undertaken by the cardiologist during later consultations, although it is outside the intended aim of the diaries to work this way, as a conversational medium.

In relation to ICD-care, others (e.g. Theuns & Jordaans 2012) have already noted how remote monitoring involves rather unclear responsibilities for action when ‘seeing patients’ as ‘virtual patients’; this is framed as a ‘*paradigm shift*’ associated with remote ICD monitoring⁶. However, I suggest that these challenges are also present in the well-established practices of short-term remote monitoring. Thus, on this parameter ICD-care does not represent something substantially new, but rather a continuation and amplification of the challenges of other scopic

⁶ It has also been shown that, despite high overall patient satisfaction with remote monitoring, many patients miss more comprehensive feedback (Petersen et al 2012).

systems. E-health, like the system P-Record, may entail further amplification of the problem of response presence. Like other e-health devices, which often are born out of a broad participatory vision, P-Record is wrapped in an overall narrative that invites patients to do more than feed the scope: providing information is also about improving communication in and between clinical encounters. Thus, clinicians may be faced with expectations of direct responses more than indirect reactions through clinical analysis based on patients' contextual information among other informational sources. All in all, what 'being accountable for responding' means is a question that transverses the scopic systems of heart care, and will be important to consider whenever the systems are re-arranged and new participatory devices put in place.

Rethinking e-health in heart care: on capacities and continuations

In this paper, I have explored a set of mundane monitoring practices in heart care that precede as well as coexist with recent attempts to develop patient-involving e-health, specifically for ICD-patients. I have deliberately drawn out similar *capacities* between the two different arrangements (that is, short-term heart monitoring including paper diaries and remote ICD-monitoring including the e-health system P-Record), bracketing differences in technical *properties*. I suggest that doing so allow us learn from well-established practices of involving patients as information providers in care schemes that, at their core, work by exceeding the physical realm of the clinic and thus ideally anticipate some of the implications of patient-involving e-health. Illuminating capacities rather than technical properties of the different arrangements requires a transversal denominator and conceptual framework. I suggest that the term 'participatory scopic devices' encapsulates these common capacities and, through its theoretical roots, can help bring forth central challenges in involving patients as information providers.

Unfolding the scopic arrangement of short-term heart monitoring overall shows how participatory scopic devices carry with them unintended overflows: because participatory devices per definition invoke patients' different experiences, logics, and concerns, what is brought into the clinic is often more – or less – than the intended information to feed the scope. More specifically, two challenges associated with the use of participatory scopic devices stand out: *how to define 'relevant context'* and *how to handle responsibilities of providing and receiving contextual information*. These challenges seem to transverse the 'mundane' practices of short-term heart monitoring and the envisioned e-health practices in ICD-care and are likely to apply to other clinical practices involving 'participatory scopic devices', although certain aspects, such as the 'fatefulness' of the scope, may be more prevalent in relation to 'scoping of hearts' than other kinds of medical scoping. Reversely, other scopic systems will exhibit unique features and implications, dependent on the 'heart of the matter' (the object and aim of monitoring - that is, what is basically at stake), the complexity of the scope, the degree to which the clinical encounters are synthetic, the temporal structure, and so forth. Importantly, short-

term heart monitoring and ICD-care also differ on some of these parameters, for instance regarding the aim of supplementing device data with contextual information. In both cases, the immediate purpose is to be able to sort and make sense of data, but the overall aims differ. Where short-term monitoring is about being able to diagnose, the ICD-monitoring is about being able to predict from an existing diagnosis, ensure the state of the device, and ultimately react when needed and *not* react when *not* needed.

Thus, while focusing on capacities and continuations potentially enables the transference of lessons between seemingly different technologies, there are also clear limitations to this strategy. Nevertheless, while we cannot presume the generalizability of the specific implications of certain participatory scopic devices, we can benefit from flagging attention to these and pose questions derived from them when studying, or designing, other devices that share their capacities. Such questions are for instance: How is the patient-generated information used and valued by different clinicians? Does this information actually make interpretation processes more manageable and valid? What difference does it make *how* patients are invited and equipped to provide information? How do patients fulfill the role as information providers and what does it imply for them?

Likewise, there are limitations to the appliance of the proposed conceptualization to the broad field of patient-involving technologies and practices, especially if one tries to match these with Cetina's framework and prime cases rigidly. Only rarely do patient-involving practices involve truly 'global' interactions that unfold simultaneously in time rather than place (video consultations are exceptions). Instead of stressing this aspect of scopic systems, it might be fruitful to stress graduations in and look out for more subtle manifestations of 'scoping', also keeping in mind that, as Cetina writes, "*even the most inclusive synthetic situation is always something of a hybrid that joins a scoped reality with physical elements*" (2009:67).

With these reservations, I believe the framework 'participatory scopic devices' to be a useful tool for rethinking e-health as continuations rather than revolution of well-established care practices. Recognizing e-health as part of a continuum of efforts to enhance the scope of the clinic and support patient participation means a shift in orientation from focusing on the novelty of e-health to investigating the workings of different socio-technical arrangements that aim at the same. 'Complex' technologies may not carry fundamentally different or more 'complex' social implications, or benefits, than low tech solutions; in any version, scopic systems have '*world-making effects*' (Cetina 2009:69) and thus provide us with important lessons. Maybe 'low-tech' devices like the paper diary have implications that we wish to avoid reproducing when designing e-health, maybe they carry benefits that *should* be reproduced or perhaps even make e-health innovation irrelevant, reminding us once again of the possibility of 'exnovation' (Mesman 2008).

Importantly, 'continuation' is not just an analytical take and understanding of the field, but also an empirical reality for individual patients whose trajectories often involve gradually being

enrolled in ever more complex heart monitoring with an increasingly enhanced scope and different (materially embedded) invitations to provide information to further enhance or adjust this scope. While short-term heart monitoring is a brief, delimited search for data, the overall diagnostic process is a more comprehensive and long-lasting one. Moreover, the monitoring often does not end with a possible diagnosis; in many cases, diagnosis leads to periodically short-term monitoring or an implanted cardiac device (e.g. an ICD). In any case, the quest for authentic data continues – it becomes chronic and so do the scope and its related synthetic situations. The scope is set up to last and often increasingly made more complex. As Cetina writes: “*the scope intimately articulates a developing fate*” (Cetina 2009:82) – here of suffering chronic heart disease and, as a result, a fate of being inscribed in chronic monitoring and taking part in feeding the scope, with or without e-health.

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Paper 2

Involving patients with e-health: the dialogic dynamics of information filtration work

Author: Karen Dam Nielsen

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Abstract

With e-health technologies patients are invited as co-producers of data and information. The invitation sparks new expectations, yet often results in disappointments. With persistent ambitions to involve patients by means of e-health, it seems crucial to gain a better understanding of the nature, source and workings of the expectations that come with being invited. I analyse the use of an e-health system for ICD-patients, focusing on how patients sought to serve as information providers. Continuing STS-research on *invisible work* in technology use, I show how using the system involved a complex work of filtering information. I argue that this '*filtration work*' was inherently *dialogic*, that is, characterized by receiver-orientation and the anticipation of response and guided by different communicative projects. For the patients, filtration work thus first of all required certain skills and knowledge about the infrastructure of care. Secondly, it entailed the expectation that the system—for better or for worse—would facilitate not just information sharing but *open up* a dialogue, which glaringly contrasted with the clinicians' expectations of being able to better *manage* dialogue. I suggest that understanding the dialogic dynamics and 'overflows' of information filtration work can help unpack the challenges of facilitating (patient) participation with e-health and other filtration devices.

Keywords: e-health, patient participation, information filtration work, dialogue

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Introduction

The basic storyline of the following anecdote may sound very familiar to readers acquainted with the field of e-health and telemedicine:

A group of researchers and clinicians set out to develop an ICT tool to involve chronic heart patients in their own treatment. Their approach is exploratory and highly user-centred. Through careful tinkering with prototypes in home and clinic, the contours are drawn for a system that will support the work of both patients and clinicians by enabling patients to provide health related information. But already in the pampering environment of pilot implementation use practices prove difficult to establish and the expectations of users and designers alike impossible to fulfil. Clinicians lose interest, patients are disappointed, and in the end everyone involved seemingly agree that this may have been a valuable learning experience, but not exactly a technological home-run in the quest for doing chronic care smarter by involving patients. *“I’m afraid that this project will end up exactly as all the others. The doctor doesn’t bother to read it, hasn’t got the time. And then you spend millions on a system which won’t work in the long run”*, as one patient evaluates.

Involving patients by means of *e-health*¹ is a persistent ambition in healthcare (Berg, 2002; Felt et al, 2009; Danholt et al, 2013). Often framed as providing win-win tools, e-health is associated with the hope that involving patients in their own treatment will improve both the quality and efficiency of care (Archer et al, 2011; Wagner et al, 2010). But realizing the ambitions seems difficult. Pilots come and go and efficiency claims remain largely unsubstantiated (e.g. Miller, 2007; Tenforde et al, 2011). The lack of evidence for e-health efficacy may partly be due to the methodological difficulties of evaluating technology outside controllable environments (Pols, 2012). But besides being difficult to measure, the win-win situation may also simply be hard to achieve. As the two examples of user evaluations above indicate, a central problem is that *people*—patients and clinicians—have to do a lot of work to make the technologies work. STS and CSCW scholars have substantiated this insight repeatedly (Mort et al, 2003; Nicolini, 2006; Oudshoorn, 2008; among others). Moreover, for people to put in the work, it must be worthwhile. So when patients are invited as participants what follows are certain

¹ I use the term e-health to denote various patient-involving information and communication technologies.

expectations—expectations which are often not met and the invitation results in disappointment.

This article addresses this well-known schism by taking a closer look at the nature and sources of the expectations that follow when patients are invited to provide clinicians with information in new ways. What kind of work does this require? What expectations are entailed? And how come expectations are so often not met despite the careful efforts of designers to create tools capable of aligning different user needs? These questions are explored through the case of an e-health system for ICD-patients and the clinicians involved in their care, ‘P-Record’², introduced anecdotally above. An ICD is an advanced pacemaker that monitors the heart rhythm and, in case of arrhythmias, treats these by electrical impulses. The care for ICD-patients is divided between 1) a specialized clinic (device clinic) responsible for the ICD-device and remote monitoring and 2) the local hospitals’ outpatient clinics (heart clinic) responsible for treating the patients’ underlying heart condition. P-Record was designed as an add-on solution to this already technologically dense and distributed care scheme and aimed at improving coordination, communication and patient participation. This overall ambition was translated into a focus on facilitating the flow of appropriate and timely information between home and clinic by enabling patients to provide information. As such, the system shares with many other e-health technologies the basic script of serving as both a standardization and customization device. That is, the system is intended as a sort of *filter* that allows information to travel from home to clinic in a structured manner that fits clinical standards while at the same time opening up for an increased involvement of the individual patient. The tension between standardization and customization has been pointed out as a characteristic of the contemporary evidence-based healthcare paradigm at once patient-centred and rational (May et al, 2006; Storni & Bannon, 2012; Moreira, 2011). E-health technologies may, as illustrated by P-Record, emphasize this tension by inviting patients to a kind of *filtered participation*. To understand the schism in e-health—the promise and expectations of patient involvement and the recurrent, subsequent disappointments—we might therefore zoom in on what this filtered participation means in practice. How is it performed, who can join, and what does it imply for patients and professionals?

² P-Record was designed through a collaborative research project, CITH – Co-constructing IT and Healthcare (www.cith.dk). The project resulted in a prototype, which was then technically implemented by a software company. The name ‘P-Record’ is constructed for the purpose of this article as a common denominator for both prototypes and the implemented system. Although this covers important differences between the various iterations, these are not the subject of analysis here and a common denominator is chosen to avoid unnecessary confusion.

The article focuses on the work that users, and patients in particular, undertake to make P-Record work as a filter. It thereby continues in the line of a classic body of literature that stresses and unpacks the hidden work of technology use (e.g. Suchman, 1995; Star & Strauss, 1999; Heath et al, 2000). However, the article also deploys a more communicatively oriented approach to the patients' *filtration work* by understanding it as a deeply interactional endeavour that involves specific dynamics and expectations³. Inspired by dialogism (Bakhtin, 1981; Linell, 2001), the article argues that providing information constitutes an intricate communicative work of assessing relevance and imagining (interactive) outcomes that in turn entails expectations of response. In other words, filtration work is a *dialogically* oriented work that involves the opening of a *conversation* and thus communicative and interpersonal dynamics that counter with and challenge the vision of scripting a structured, standardized information sharing practice, as well as individualized ideas of e-health as facilitating self-care.

The article is structured as follows. I first draw up the framework for the analysis by discussing P-Record's script as an information filter and subsequently outlining the article's core conceptualization: 'filtration as dialogic work'. After describing the applied methods, I turn to the analysis in which I unfold patients' and professionals' use and valuations of P-Record, showing the dialogic dynamics and derived implications involved in making P-Record work as a filter. In conclusion, I discuss the implications of the findings for e-health as well as the wider utility of the applied concepts.

Filtering information between home and clinic

While P-Record was designed to support the flow of information both between different clinics and between home and clinic, I focus on the latter script (Akrich, 1992) and the associated practices. I propose to describe this script in terms of an information *filter*; that is, a device that allows certain information to sift through and other information to be left out⁴. In information science the notion of filtration is central, typically referring to a method for the delivery of relevant information as one strategy among others for dealing with information overload—filtration being the process of "*leaving some types of*

³ Contrary to the often noted performative role of expectations in innovation processes (Borup et al, 2006), the case of P-Record is rather a story of the simultaneous fuelling and 'failure of expectations' (Brown & Michael, 2003).

⁴ The term 'filter' relates closely to such terms as 'sorting', 'sieving', 'retrieving' and 'selecting'. I use the term 'filter' since it is already commonly used in relation to information and communication technology and thus constitute a 'native' metaphor. I use both the noun and verb form in order to capture the tension between perceived automatized 'filters' and the practices involved in making them function as such.

information unprocessed, according to some scheme of priorities” (Savolainen, 2007:612—paraphrasing Miller, 1962). Depending on the specific approach, filtration is understood as a cognitive and/or social process that can be more or less supported or substituted by technical systems with the aim of “*automatically directing the most valuable information to users (...) helping them to use their limited reading time most optimally*” (Hanani et al, 2001:203). Information filtration devices are manifold: spam filters and customized search engines are just some of the more mundane examples. These examples, however, also incarnate features and dynamics that may apply to other domains, as we might understand filters—or sieves—broadly as technologies of ‘ontological transformation’ (Kockelman 2013). Indeed, while filters may be understood as “*the simplest of interpreting agents*” (p. 37), *meaning* is also “*the quintessential form of sorting*” (p. 39). As anthropological concepts, ‘filters’ and ‘filtration’ may thus describe how we order information and produce meaning in general.

The filtration terminology—in its more modest version—is also present in the field of e-health and telemedicine. A predominant narrative here is that filtering information is both *necessitated* and *enabled* by new technologies (Berner & Moss 2005; Eysenbach, 2008). That is, visions of e-health/telemedicine often involve a dual promise of increasing the production and accessibility of data and solving the subsequent need for filtering the vast amount of data made available in order to “*provide meaningful quantities of health information to both patients and physicians*” (Warren et al, 1999, my emphasis). Importantly, information filtration is recognized as an already crucial part of medical work where decision-making in a terrain of informational pluralism and uncertainty is a precondition. However, in the light of what has been called a ‘patient information explosion’ (Berner & Moss 2005), the call for formal filtration tools intensifies. Yet, the filters that are subsequently put in place with e-health/telemedicine can also be perceived as being too efficient: they may cause vital clinical information to be left out (Lehoux et al, 2002), thus not solving but in some cases rather reinforcing the “*struggle between information loss and information gain*” (Mort et al, 2003:292).

P-Record as an information filter

Although the term ‘filter’ is not explicitly used in the design of P-Record, the system materializes the co-creation of the problem and solution of obtaining and restricting information—of what to let in and leave out. First of all, the system was meant to support the automated production and filtration of data involved in remote monitoring. Every third month the data continuously collected by the ICD-device are transmitted through a communicator box in the patients’ homes to the device clinic where they are analyzed by specially trained technicians (assisted by cardiologists). Data can also be acutely

transmitted if either the patient or the ICD detects a cardiac or device event. Patients still visit the device clinic for semi-annual follow-ups but before the introduction of remote monitoring every ICD follow-up required a visit to the clinic. The core idea with P-Record was to provide clinicians with *contextual information* from the patients to be used in the interpretation of remotely transmitted data, that is, the patients' own accounts of general wellbeing, symptoms, and events. With the introduction of remote monitoring, this information—normally articulated during face-to-face encounters—has been 'filtered out'. Furthermore, automated data filters built into the monitoring system filter the raw data that are transmitted to the clinic, highlighting severity and character of recorded events. While this filtration makes the vast amount of data that is transmitted more manageable and potentially reduces the workload (Sinha et al, 2006), it also leaves the technicians with an interpretative uncertainty. In the face-to-face encounters the technicians match the system's indications with contextual information, often leading the technician to reassess the automated filtration. In the absence of the patient this reassessment is not possible. P-Record was an attempt to reintroduce the patient as information provider (or "*diagnostic agent*"), enabling yet again "*interlinked processes of interpretation*" (Andersen et al, 2011a:6). With the aim of providing technicians with the contextual information otherwise 'filtered out' by the telemedical setup, P-Record can thus be said to be designed as an *adjustment* of the overall socio-technical information filtration in ICD-treatment.

Secondly, the system was designed to *focus the face-to-face clinical encounters* at both the device clinic and the heart clinic by providing a tool for preparation: the *preparation form* (figure 1). It consisted of four parts: general well-being, status since last consultation, symptoms, and questions for the upcoming encounter. The parts and their order were designed in a way that allowed for free text in the first part, then gradually narrowing down the patients' entries by asking the patients to write key words and arrange them after priority and subsequently to indicate symptoms by ticking off boxes linked to prefixed categories. The preparation form would thereby enable the clinicians to gain a quicker overview and focus the conversation with the patient—to "*get to the point*" (Andersen et al, 2011b)—*and* allow the patients to present their own narratives. This way, P-Record can be understood as in itself designed to both open and narrow the scope of information and to assist both clinicians and patients in their informal filtration of information before and during the clinical encounter—a 'dual filtration script' that P-Record shares with other e-health systems (e.g. Basch et al, 2005).

The figure consists of four screenshots of a web application for preparing a medical record. Each screenshot shows a different tab of the 'Forberedelse' (Preparation) form. The tabs are: 'Alment' (General well-being), 'Siden sidst' (Status), 'Symptomer' (Symptoms), and 'Spørgsmål' (Questions). The 'Alment' tab includes fields for appointment type, date, and time. The 'Spørgsmål' tab includes a list of questions. The 'Siden sidst' tab includes a list of symptoms. The 'Symptomer' tab includes a list of symptoms. Arrows indicate the flow between the tabs.

Figure 1. P-Record's preparation form. Consisting of four parts (besides the front page indicating the type of appointment): *general well-being* ('alment'), *status* ('siden sidst'), *symptoms* ('symptomer'), and *questions* ('spørgsmål') - in the example, partly filled out by patient-participants in the user-test (personal information concealed).

'A filter' is a rather material figure, indicating a fixed structure that firmly defines what is let through. As such a filter can be seen as a mechanical standardization device. In parts of the literature, it seems that e-health technologies are expected to work as filters 'by themselves'—as ensuring through the materiality of their design that just the right amount of information is enabled to travel from home to clinic. In the case of P-Record this expectation was also present among clinicians, as will be shown in the analysis. P-Record's script, however, also involves a promise of empowerment and customization by inviting patients to provide their own illness narrative and put individual concerns on the agenda. This invitation brings an ambiguity to the script, which in practice leads to the material filtration script being fundamentally challenged. As a filter, P-Record does *not* work on its own. Users have to act in certain ways to make it work: they have, I propose, to perform a filtration work. Although phrased differently, this also resonates with how

the designers originally envisioned P-Record as assisting, but not fully determining, “*a process of formalization*” of patient information (Andersen et al, 2010, adopting the concept from Berg, 1997) requiring that clinicians still perform a *translation* and patients are *trained* in shaping information.

Filtration as communicative work

By directing analytical attention to the filtration *work* involved in the use of P-Record, I place the analysis within a practice-oriented framework. I approach filtration as a socio-technical and transformative *process*: a “*subset of information and retrieval practices*” (Leaver et al, 2012, my emphasis), which further can be understood as a specific kind of work, namely communicative work. In framing filtration as work, I draw on a valuable strand of STS-inspired research into telemedicine and e-health that has shown how informal or invisible work (Star & Strauss, 1999) is required of both patients and professionals to make use and sense of new technologies (e.g. Mort et al 2003; Oudshoorn 2008; Piras & Zanutti, 2010; Pols 2012; Roberts et al, 2012). These studies have also given insights into the (re-)distribution of work that is entailed in using telemedicine (e.g. Oudshoorn, 2011). Work, in this line of studies, is used to describe users’ practices of domesticating and tinkering with technologies (Langstrup, 2008; Pols & Willems, 2011), producing knowledge (Mort et al, 2003), building relations and infrastructures (Oudshoorn, 2008), and coordinating and performing care (Langstrup et al, 2013).

I seek to further concretize the notion of work by proposing to look at the use of P-Record as *communicative* filtration work and subsequently unpack the inherently interactional practices involved in using ICT. I do this from a dialogic perspective. A common and basic feature of the multitude of approaches that label themselves ‘dialogic’ or ‘dialogism’ (e.g. Bakhtin, 1981, 1986; Linell, 2001; Phillips, 2011) is the onto-epistemological claim that human cognition and interaction are dialogic in nature. For the purpose of the following analysis, I focus on and adopt the most basic analytical figure of dialogism, namely the claim that every utterance is defined by other-orientation or *addressivity* (Bakhtin, 1986:99); that is, inherently targeted towards a receiver. Producing an utterance thus involves the anticipation of its prospective interpretation and continuation—in short, “*what is going to follow*” (Linell, 2001:100). This claim, I propose, resonates with and usefully sheds light on the use practices that went into making P-Record work as a filtration device. As Maurer (2013) puts it, filtration – or *sieving* - “*depends on a set of presumptions, a priori judgements or assessments of probabilities*” (p. 65). That is, filtration rests on certain ontological assumptions. These are both transformative and continuously transformed by inference (Kockelman 2013):

we order our worlds based on our assumptions – including assumptions about others’ assumptions – but our encounters with the world (and others) provides for recurrent reinterpretations and new assumptions. We adjust ourselves as filters, so to speak. I show how the specific filtration work that the users of P-Record performed was based on *dialogic* assumptions: it consisted of processes of imagining the receiver, the interactional situation, and the response—and shaping ones entries accordingly. Filtration work, I suggest, is thus a dialogic endeavour. And as a dialogic endeavour, filtration work entails certain dynamics and ‘side-effects’ making the use of P-Record a complex and, in some instances, quite problematic social practice.

The dialogic approach largely resonates with studies in ethnomethodology and, later, in CSCW that unpack the social dynamics of producing and sharing medical information. In his seminal study of practices of keeping medical records, Garfinkel (1967) precisely demonstrates how, in this case, *doctors* shape their entries based on anticipation of the future readers’ interpretation and use and, recursively, read entries in recognition of their occasional rather than intrinsic meaning. In CSCW, this insight has been a key to understand the challenges of digitalizing medical work. As demonstrated by for instance Heath & Luff (1996) and later Berg & Goorman (1999), digitalizing and thereby formalizing medical records clashes with the social and contextual nature of medical information. That is, ICT risks impeding rather than supporting the flexible, situational and receiver-oriented record keeping practices, which build on a shared, tacit organizational rationale rather than formal standards. When studying the use of ICT’s that also include *patients* as information producers, I propose that a dialogic framework very precisely brings forth the challenges and implications of coordinating information filtration practices in the absence of a shared organizational rationale.

Methods

The article is based on ethnographic research conducted during a 3-month user test of P-Record. The user test involved 6 patients and 6 clinicians at the outpatient heart clinics of two Danish hospitals. During the user test, patients were to prepare for and participate in three kinds of clinical encounters using the IT-system: a remote follow-up of their ICD, an in-clinic ICD follow-up at the device clinic, and a consultation at the local hospital’s heart clinic. These activities together constitute the existing distributed care scheme of ICD-patients. However, due to the timeframe of the user test, these activities were rescheduled to take place closer to each other in time than normally. Throughout the user test, I acted as facilitator and instructor. Patients were given instructions in their homes. All parts of the system was demonstrated at the initial visits, although with an emphasis on the more extensive functionalities (the *preparation form* and *medication list*) linking to

upcoming appointments in the clinics. The visits also involved interviews with the patients. Likewise, the system was demonstrated to clinicians individually, however, in a briefer manner due to the limited time available in the clinics and the knowledge of the system that they had already gained through their participation in the design process. During the user test, I accompanied the patients at their visits to the clinics and had telephone and/or email contact with all patients on more occasions. By the end of the user test all participants were interviewed about their experiences during the test.

By serving as *both facilitator and ethnographer*, I took on a highly interventionist approach. To turn the challenges of this approach into analytical resources, I treat the user test of P-Record as both the object of study and a heuristic device—a transformative *filter*, so to speak—allowing me to gain understanding by disruptively bringing about more nuanced data (Hasu & Miettinen, 2006) and engage with frictions (Zuiderent-Jerak & Jensen, 2007). As part of the following analysis, I thus draw on the insights gained as I became a central knot in the infrastructure and interactions and thereby experienced firsthand the dialogic dynamics involved in the use of P-Record.

The analysis is structured as a gradual unfolding of these ‘dialogic dynamics’ by following the flow of interactions between patients and clinicians as they took place during the user test. In the first section, I show how patients made use and sense of the tool as a way to address clinicians. I then show how clinicians perceived and responded to the patients’ entries. Finally I turn to how patients perceived the clinicians’ reactions. At the end of each section I discuss how the (dialogic) use practices can be understood as filtration work.

Writing to someone

The design of P-Record only vaguely indicated the identity of the receiver of patients’ entries. However, a defining feature of how the patients used the system was that they addressed their writings to *someone*: either a specific receiver or a generalized receiver. Proceeding from this observation, I propose that the patients’ use of the system was characterized by *addressivity* (Bakhtin, 1986; Linell, 2001): their entries were directed towards a receiver with the anticipation of a response and shaped accordingly. That is, in deciding on what to write about patients performed a *dialogic* assessment; they based their assessments of relevance on careful considerations about *whom* they were writing to, *what* the receivers might want, and what kind of *responses* to expect. This dialogically oriented process of shaping entries proved a complex interpretative task of de-scripting not only the system but also, and especially, the *context* of use—that is, the overall practices and infrastructures of care that make up the ‘real environment’ that P-Record only vaguely describes (Akrich 1992).

Knowing the receiver

During the user test, patients were to prepare for three different clinical encounters. The preparation form was, however, generic; there was no technical shaping of the patients' entries according to the different kinds of consultations. Instead, the patients took on the work of filtering information for the different consultations by trying to envision who would be at the other end and what information this person would want, also involving envisioning what actions could be taken. Therefore, the work of filling out the preparation form first of all became dependent on how clear the division of work between different clinics and professionals was to the patients. Some patients were well aware of the infrastructure, as the participant Anne (a health professional herself and long time ICD-patient) who even knew, in details, about the distribution of competencies among named clinicians in the same unit. When filling out the first part ('general well-being') of the preparation form for remote ICD follow-up, she stated *"is doing fairly well"* despite being troubled by various symptoms on a daily basis. When I asked her about her choice of words, she said:

"The problem is that is only our technicians (who reads it), right. They can't.. it is only about the technical side of the ICD, right. That is why I said to you on the phone: but who sees it? None of the doctors do. They (the technicians) can't go into all that, neither regarding my medicine or symptoms or how I have been feeling." (First interview with Anne)

Later, when preparing for the in-clinic ICD follow-up, she writes that she is experiencing nuisance in her right shoulder and neck caused by the device pressing on a vein. But she is in doubt about the relevance of raising this issue:

"It doesn't help to talk to Mark about it. Then I would have had to get an appointment with.. then we should have called in John (cardiologist). But it wasn't that important, I think.(...) If it was a real system that was up and running then we would have to talk about it. But then I would probably have called them (...) because usually when you're at the clinic for a reading then it is not supposed to be a conversation with a doctor or a talk at all." (Final interview with Anne)

Anne here assesses the meaningfulness of raising the issue based on well-founded assumptions about the receiver, considering both if the receiver will be able to act on it and if the severity should spark her to try to address another potential receiver by other means. She thus pragmatically draws on her extensive knowledge about the division of work in the clinic. And in the end, her interpretation of the infrastructure of care seems to lead her to make a shift in perception from regarding the clinical encounter as the context

of use to seeing the user test as the context or purpose in relation to which she assesses the relevance of her entry. As she explains when asked why she chose to raise the issue about the neck vein after all:

"I think it was just as much because I had to write something (laughs) so that we would have something when we got there (to the first test consultation at the clinic)." (Final interview with Anne)

For other patients, the distributed care scheme and lack of a regular contact person among the clinicians caused greater uncertainty about who one was to address and, consequently, what would constitute relevant information. This was strikingly evident for the participant, Ben, who to some extent had given up on understanding the infrastructure. Therefore, when filling out the preparation forms for the three different appointments, he did not address a specific receiver but wrote with a collective, cross-institutional, and "typified" (Linell, 2001:103) receiver in mind—"the doctors"—although he had experienced this collective as highly fragmented:

"Interviewer: And does it mean anything to you who will read it at the other end? Ben: I almost don't care when it comes to the doctors. (The local hospital) and (the device clinic) each have their own opinions, that is for sure." (Final interview with Ben)

Ben's way of using the system shows, in an intricate way, how the directness towards a receiver is both inevitable and highly challenging. He may not be addressing a specific receiver but he nonetheless writes from an experience that it *does* matter which clinicians he is in contact with in terms of which interpretations and decisions will be made, that is, how his utterances will be filtered differently by different receivers. On the one hand, his lack of knowledge about the division of work between the different clinicians meant that relevance became hard to assess and he repeatedly consulted me for advice on what to write. Even at the end of the test period, when filling out the preparation for a visit at the heart clinic, he was still very insecure about what to write although he could now draw on experiences of what had proved relevant—or irrelevant—to other clinicians at previous encounters:

"Ben: 'How have you been since the last time?' Well, what should I say? What should I write now? (...) I would like to have a day monitor put on, now that I'm working, to see the next 24 hours. Interviewer: You could write that as a question, for instance 'Can I have a day blood pressure monitor put on?' Ben: Yes, that's what it said here (in the preparation form) the last time I was at (the device clinic), but as she (the doctor) said, it was (the local hospital) who handled that case." (Extra visit and instruction with Ben)

Provided with a new means of contact (P-Record), Ben also on his own initiative attempted to bridge what he experienced as a gap in the infrastructure causing him great anxiety. Requesting to have his blood pressure measured over the course of a working day—something he had discussed with his GP—in his preparation forms for his appointments at both the heart clinic and at the device clinic can be seen as a persistent attempt to make the issue a shared responsibility across institutional boundaries. And perhaps more distinctly, he used the system to navigate in the complex infrastructure by directly addressing *me* through the e-mail feature (e.g. with questions regarding appointments outside the context of the project and by forwarding referral letters asking me to help make sense of them), thus making me at times the primary and only specific receiver. Ben this way, like Anne, partly shifted his orientation from the clinicians as receivers and the clinical encounters as the context of use to the researcher and the research project—in his case, because the infrastructure remained incomprehensible to him.

Anticipating the answer

Besides considering who the receivers might be and what they might want, the patients shaped their entries according to reflections on what response they might get and, more subtly, how they would be perceived as a sender and how they wished to perceive themselves. For the participant, Carl, these considerations all come together when he is filling out the preparation form for the consultation at the heart clinic and together with me tries to establish what would be relevant to write. Carl takes into consideration the severity of certain health issues and relates it to his knowledge of the division of work between the cardiologist and his GP. He has had a cough recently but does not think is severe and is therefore content with already having discussed it with his GP—“*it’s nothing to start ranking up*”, he says. His assessment of what is relevant to write is further influenced by his overall experience of illness: how certain symptoms become part of ‘the normal’ and how he is coping with illness by insisting on a good general well-being:

“Interviewer: If what has characterized the situation the most is that you have felt short of breath, then you could write that. Carl: Well, yes, but they know that because it has been like that for many years now. (...) Interviewer: And then there is the option to write five things, but you don’t have to write five things. Carl: No, no, no, because I feel fine. But, well, there is just.. when I bike or (walk) up the stairs then I pant a lot, right. That’s the only thing. Because otherwise I feel alright. There’s nothing the matter with me.” (First visit and instruction with Carl)

Later, when filling out the preparation form himself before the consultation at the heart clinic, Carl first states that he “*is doing fine*” but when asked directly about symptoms he ticks off almost all boxes: shortness of breath, dizziness, swollen legs, palpitation, and fatigue. On the last page of the online preparation form (questions for the consultation), he repeats “*shortness of breath*”, “*dizziness*” and “*swollen legs*”. He later explains that he would not normally take these things up as he has just conformed to them as conditions and only thought of them because P-Record provided the keywords. This way he acts according to the script of the system in the sense of being sparked to articulate symptoms that he would normally remain silent about – to adjust his usual filtration by letting *more* through. At the following visit the cardiologist asks about the symptoms and touches upon lifestyle issues. However, Carl just comments and nods evasively and disinterested and afterwards states that he knows all this, they have talked about it before, but he prefers to continue his lifestyle and just enjoy whatever time he has left. He adds that he would not find the system meaningful outside the realm of a research project; he is happy with the existing care scheme to which he complies. For Carl, the very act of writing about symptoms conflicted with his choice not to focus on illness and furthermore sparked the articulation of lifestyle issues at the consultation that he regarded as pointless and merely tiresome to address repeatedly.

Carl’s case thus points to a consideration that may be part of patients’ filtration of information, namely the wish to minimize the focus on disease. Carl’s way of assessing relevant information when shaping his entries mirrors his way of communicating with clinicians in general and can be described as a balancing act between providing the necessary information and keeping symptoms unarticulated—the goal of the balancing act being to cope with illness in a way that minimizes its overall impact in everyday life. He thus filters information with the prospective continuation of the dialogue in mind—imagining not only who the receiver might be and want, but also considering what kind of conversation his entries will lead to and subsequently how this will (negatively) affect his overall coping with illness.

For other patients, imagining what their entries would entail played out as attempts to foresee more specifically what kind of answers they might get from the clinicians. Anne, who chose to raise the issue of a nuisance around her neck vein caused by her device, anticipated that she would not get a response since the issue would be outside the scope of the receiving technician’s competences. She also expected that there simply would not be time to respond for the receiving clinicians in the device clinic since “*they already have plenty of work with all that remote monitoring*” and using P-Record would “*take a lot more resources*”. Besides drawing on these assumptions about the conditions of work in the clinic, she furthermore based her anticipation of response on an assessment of

severity; that is, if a certain issue would be considered topical and serious enough by the clinicians to be acted upon. In a circular way, she links her assessment of what the clinicians may regard as serious to the choice of media: using P-record to raise a certain issue may in itself indicate to clinicians that it is not something they need to respond to. As she says:

“If I can be content with sending a message then it’s not that serious, you know, then it’s not something they have to act on here and now. Because if it was serious then I would get on the phone and call them or I would rush off (by ambulance).” (Final interview with Anne)

Finally, Anne takes into account that the issue may not be ‘actionable’ (Andersen et al, 2014) at all. That is, the answer she has been given so far is that nothing can be done about it. This adds to her anticipation that raising the issue of her neck vein will not spark an answer in the hoped-for-sense—that is, some kind of clinical action that will solve the problem—and thus not be worth the effort.

Experimenting with dialogue

In her writings and deliberations, Anne is constantly torn between pragmatic expectations and a wish to experiment as a participant in a user test. Contrary to the script of the system as a means to ‘open the scope of information’ in relation to remote monitoring especially, Anne chooses to write more extensively to the in-clinic follow-up. Imagining the interactive situation, she concludes that if she is to write something in P-Record it will make more sense for her to provide information when it can actually become the basis of a conversation:

“I can’t talk to them in connection with the preparation for (remote device control) so I wrote generally.(...) When I thought about, okay the third of December I am going there (to the clinic), then it was important to include other things, symptoms and so on.” (Final interview with Anne)

For her, the potential lies in the hope that providing more information will lead to a richer (face-to-face) conversation. This goes for the patient, Louis, as well. At first glance, he seemed to do ‘less’ filtration work compared to the other patients who all wrote in a very

concise manner. Louis wrote extensively in both the preparation form and in the logbook⁵ and, in the eyes of the clinicians, really “*opened the floodgates*” with entries like this:

“I continue with dizziness and general fatigue which sometime gets really bad, other days is okay. I have arrhythmias many times a day, especially when I rest. Haven’t experienced it while I walk or anything else. The legs are always weak and of course with great difference in temperature. The right leg feels numb sometimes. That may also be due to the lack of vitamin D since I stopped taking them in December.” (Louis’ logbook, symptom note)

He did, however, still perform a selection of information, only he regarded the system as a chance to open rather than narrow the scope and provide the information which he was afraid was missed in the existing care scheme. Like for other patients, the distributed and technologically dense character of ICD-care made Louis feel that no one saw the full picture of his condition and treatment and that crucial information was lost. In his case, the infrastructure was complicated by his participation in a clinical research project where he underwent additional in-clinic device follow-ups as well as various blood tests, measurements, and scans. Although he could be said to be under closer surveillance through the project, all the extra data produced only caused frustration and uncertainty since he experienced that they were neither shared with him nor with the clinicians responsible for his treatment. On this ground, Louis’ extensive writings—together with his persistent suggestions to add a file-sharing feature for test results to the system—can be seen as his attempt to mend a severely flawed information infrastructure. Thus, he *does* undertake filtration work by trying to assess the value of the information he gives and, reversely, the risk of leaving out information. He writes from the hope of receiving better answers by providing more information but is at the same time rather pessimistic, worrying that the clinicians will tell him that they “*don’t want to hear that story anymore*”.

To Louis, the system provides, if not a promise of resolving his uncertainties, then a *chance* to make the clinicians take on responsibility and sort out his concerns. Like Anne, Louis chose to *experiment*, testing new possible questions and responses in the clinical encounter. They both raised more issues than they actually anticipated a response or *reaction* to and thus did not just interpret the context of use in light of existing practices,

⁵ In the *logbook* patients could write free text categorized as either *diary*, *note of symptoms*, or *illness history*. This part of the system was not explicitly associated with upcoming appointments but the entries would nonetheless be visible to clinicians.

but also tried to push the receivers towards new practices by addressing them in new ways and with otherwise neglected issues.

Addressivity as filtration work

A main intention with P-Record can be described as to ‘lure out information’ in a strictly focused manner. The work of filtering information is to some extent built into the system with the structure of the preparation form aimed at gradually narrowing down and formalizing patients’ narratives. However, most of the patients pre-empted the focusing questions by deeming most of what could be written as irrelevant and writing in a concise and brief style in all parts of the preparation form. Rather than being restricted in their writings by preset limitations of the system, they seemed to restrict themselves according to their assumptions about the receiver, interactive situation and possible outcome. The patients’ writings (even the more extensive ones) were shaped through communicative work based on an understanding of P-Record as a tool for opening a dialogue rather than ‘pure’ information sharing. The information they provided was a product of receiver-oriented filtration work, instigated, partly supported, but far from ‘automatically’ performed, by the device.

Receiving and responding

So how did the clinicians use and value the information given, and how did they respond? The clinicians’ performance as receivers and responders can be understood as an enactment of their descriptions of P-Record as a filtration device, as well as their ‘responsive attitudes’ (Linell, 2001:104).

P-record as a filter (and receiver) in itself?

At the local hospital the cardiologists attempted to use the system to focus the face-to-face consultations and thus valued the patients’ entries accordingly. In some cases they perceived the entries as containing surplus information but were satisfied with the way the system then allowed them to screen this out and “*get to the point*”. In other cases they perceived the patients’ entries as a satisfying way of getting the information that they need but often have to work hard to obtain from some patients. One of the cardiologists summarized the value of the system as a means to both opening up and narrowing the scope this way:

“You could use it both ways, really. To get the swarm of thoughts that occupies some patients under control, where it just pours out of them. And then with this guy (the patient

Carl) it was more the case that if you ask (then he answers) 'it's going well' and (you say) 'okay, then we don't have anything else to talk about'. He would be the kind of guy who then comes home and the wife asks 'why didn't you ask about all these things' or where it pops into his own mind 'oh, maybe I should have asked about something'." (Final interview with Peter, cardiologist)

Two cases lie behind this statement. One of them is Carl who, provided with keywords in the preparation form, articulated more symptoms than he normally would do at a face-to-face encounter. When evaluating the system later on, the cardiologist highlights Carl's case as an example of the potential value of the system as it allowed him to get information about symptoms that he would normally have a hard time getting Carl to talk about—a 'success' that the cardiologist also tries to share with Carl at the consultation:

"Peter: Do you have anything else on your mind? Carl: No, cause I feel fine. Peter: Yes, but that's kind of funny because I can see that you write that you are feeling fine but then there was something about being short of breath and there was something about water in your legs. Carl: Well, yeah.. Peter: But it's fine that you are doing well, but still, now we can adjust the details a bit, right. Carl: Well, I just thought that I'm so used to being short of breath so you just cope, right." (Transcript, Carl's visit to the local hospital)

The other case, initially referred to, is Louis, who wrote extensive entries in an attempt to ensure the articulation of crucial information and to push the clinicians to provide the answers and actions needed to reduce his anxieties. At the consultation the cardiologist only took up a few of the issues Louis had raised in the preparation form and later described Louis' entries as *"very unstructured with these novel-like or diary-like entries that I can't live up to"*, also referring to them as *"solemn phrases"*. Despite his critical attitude towards Louis' writing style, or exactly *because* of this, he thought the system proved useful in the situation by allowing him to *"control the contact"* by quickly screening the information given and avoid its articulation in the brief consultation, thereby perceiving P-Record as facilitating a win-win-situation:

"He had kind of got it out. (...) Then it was like he knew that I knew a whole lot, which we then didn't have to sit and start all over on. So this way I actually think that the patient is allowed to get rid of it and I'm allowed to hear it without it taking up too much space. Then they get what they need and I get what I need. I need something more structured and concise.(...) If he should sit and present a bigger dramatic contribution in the consultation then it would come between us." (Final interview with Peter, cardiologist)

The cases illustrate how the cardiologists seemed to consider the system, at best, as a *filter* that allowed them the information they needed to respond to the patients' heart condition and not their general concerns. They further seemed to perceive the system as an adequate *receiver in itself*: that patients would feel good just getting something off

their chest by writing about it and that the clinicians then would not have to spend time on responding to (for them) irrelevant matters. The cardiologists thus regarded P-Record as a filtration device able to remedy existing problematic filtration practices and assist them in their own filtration work. As such, P-Record succeeded in the concrete cases, yet, it did so by also rendering the patients' filtration work 'functionally invisible' (Star & Strauss, 1999) and thereby masking the dialogic imaginations—or expectations—entailed. However, the cardiologists *did* worry that, at worst, they “*would actually be tested in if (they) had read and understood it all*” by the patients, whereby the system would fail as a filter.

Shifting responsibility

At the device clinic, the participating technician, Mark, differed from the cardiologists in his responsive attitude, being eager to provide an answer although this was no straightforward task. The system meant that some patients would raise concerns that seemed to exceed the kind of medical analysis and decision making normally included in his job. This caused insecurity in relation to answering, as in the case of his remote follow-up of Anne where I accompany him:

*“Interviewer: What she has written in the preparation (form) – isn't that relevant for you?
Mark: Well, yes, but she's feeling all right.. If she writes 'my legs are swollen' then I have to get a doctor and say 'look here, you have to write to this patient'. Or if the patient writes 'I've had extra heart beats' or something like that, then it can be related to the arrhythmia. So in that sense it does matter to me, right. Interviewer: But is it then something you have to act on now when she writes about feeling a pain around her neck vein?(...) Is that something you would normally decide on? Mark: No, because she has made a sending (remote transfer of ICD data). Now, it's just that she writes.. Well, I would write a message to her 'if the swelling and pain around the neck vein continues you should contact us'. That's what I would write. (...) Yeah.. but.. should we write something to her?”* (Transcript, remote follow-up of Anne's ICD in the device clinic with Mark)

However, by being able to write a message saying “*call if the problem continues*”, Mark was also relieved from responsibility for further reaction, as he could pass this on to the patient. For Mark, passing on the responsibility for reaction became a way to 'filter' the patients' concerns one more time. This filtration both served to help him in his medical decision-making, based on the rationale 'if it is really important they will call' (as illustrated by Anne's case), and to save time:

Mark: You can communicate quickly (with P-Record). Right now we have a problem with a patient who does not answer his phone. Then you spend a lot of time calling the patient again and again. If he had this system then we could have said "please just call us", right.

(...) So you can say, it's up to the patients (who) also have certain obligations themselves. It's their disease, it's not ours. If they had this (P-Record) and something came up then they would have to go in and tell us if there has been anything. (...) But he hasn't contacted us, the guy from yesterday, so he can't be doing that bad. (Final interview with Mark)

Filtering to manage the dialogue

As a filtration device, P-Record successfully assisted both the cardiologist and the technician in managing responsibility “*in a field riddled with uncertainty*” (Jerak-Zuiderent, 2012:738). For the cardiologists, P-Record lived up to their expectations as it supported them in their efforts to respond only to issues within their specialization. The cardiologists seemed to perceive P-Record as a more or less ‘automatized’ filtration device, not recognising the filtration work done by patients (and its implications) as a crucial part of making the system work (or not). On the contrary, the cardiologists evaluated the system in terms of how well it succeeded in filtering the patients’ narratives, thereby supporting them in obtaining just the right amount of information to inform clinical decision-making and “*control the interaction*”. As a filtration device, P-Record also proved a valuable tool in the work of the technician in his ‘frontline’, experimental attempts to sort urgency from non-urgency and restrict access to specialists – to “*act while trying to know*” (p.742). In assisting him in filtering information, P-Record also became a means for filtering *access* to the clinic, as he could use the system to push the interactive initiative back to the patients and to another medium: the telephone. This way P-Record became an additional layer in the existing filtration of the contact between home and clinic, and although not an explicit design intention, the system then came to hold another common e-health script as an ‘access filter’ (e.g. Moreno-Ramirez et al, 2005).

Continuation of the dialogue

In their evaluations of the clinicians’ responses, the patients were torn between pragmatics and disappointment. I suggest that this links back to how their filtration work rested on addressivity and thus entailed drawing on previous experiences of what one can expect (or not) from certain clinicians *and* a basic expectation of response inherent to the opening of a dialogue.

Realism, hope and disappointment

Although presented with a system that seemed to promise an improvement of communication both ways, several patients indicated that they, for various reasons, did

not really *anticipate* an answer after all, as illustrated earlier and especially clear in the case of Anne. Besides her awareness of the constant lack of time in the clinics and the limitations of the receiver's ability to act, she also recognised the issue of her neck vein as simply unsolvable. This realism led to rather low expectations in the concrete situation and she evaluated the answer she was given accordingly:

"Interviewer: Then Mark wrote to you after the remote reading? Anne: Yeah, he sent this (reads out loud from the screen): 'Your transmission has been read, everything found okay. If swelling and soreness is persistent, please contact us'. But he can't do anything about it. Interviewer: No. So what do think of an answer like this? Anne: Then I say, well, they know and what are they going to do about it." (Final interview with Anne)

Being *realistic*, in the sense of understanding and taking into account pre-existing realities like the infrastructure, the qualifications and attitudes of specific clinicians, and medical circumstances, to some extent seemed to minimize disappointment. As I have shown, the patients who took these realities into account seemed better able to address the clinicians in a manner that the clinicians appreciated: they wrote in a concise manner and held what turned out to be a realistic vision of what outcome to expect. In contrast, Louis and Ben, both relatively new ICD-patients with little experience of the 'realities' and an urgent need for contact, wrote extensively and without a specific (named) receiver in mind hoping to spark a reaction from the collective of clinicians or 'push realities', but with little effect.

However, all patients *did* on some level *expect* an answer and expressed being discouraged by the (lack of) response given. As Anne states, despite her pragmatic attitude and awareness of the "realities":

"I would like to use it (P-Record) but then I want some response to what I have written. If I ask some questions or have some problems in relation to my heart condition or my ICD then I want either time in the clinic or a response from them. That requires that the staff will do this seriously." (Final interview with Anne)

For some the disappointment first of all seemed to be caused by the response not entailing the hoped-for action, as in the case of Ben, who in his preparation for his consultations at both the device clinic and the local hospital had asked for a 24-hour blood pressure monitor and asked for advice regarding an over-the-counter drug. At the device clinic the technician and accompanying cardiologist did not explicitly take up any of the issues and only gave a brief answer when Ben asked directly, saying that these were matters for the local hospital to handle. At the local hospital the cardiologist did address Ben's request for a 24-hour blood pressure monitor but simply did not agree with it. He also browsed

through Ben's medication list⁶, suggesting a few adjustments, but not addressing the issue of the over-the-counter drug that Ben has listed with a question mark. The fact that the action he requested was not taken and the issue of medication not explicitly addressed left Ben with a feeling that his preparations had been useless. For Ben, P-Record did not facilitate a more coherent dialogue across institutional borders as he had hoped for and it did not lead to the hoped-for action thereby in sum not reducing his concern that no one was taking responsibility for his overall situation.

For others, disappointment seemed more about not feeling heard at all. Having written extensively in the preparation for his consultation at the local hospital, Louis was hugely disappointed with the verbal response he got from the cardiologist as expressed in his later imitation of how the cardiologist, only looking at the screen, quickly browsed through and subsequently disregarded the issues he had raised:

"Maybe it is easier for the doctor himself to have this little system (...) then it is much easier for them to say, 'okay, bla-bla-bla-bla-bla'. (...) I looked forward to this consultation (but) it was more like an IT-consultation, as I call it. (...) I call it an IT-consultation when a doctor doesn't bother to listen and he just sits in front of you and says 'okay, so and so and so'." (Final interview with Louis)

Clearly, Louis did not support the cardiologist's appraisal of P-Record as allowing both patient and clinicians *"to get what they want"*. To Louis, just *"getting something off his chest"* without subsequent articulation during the consultation was far from satisfying.

Filtering to open up (a better) dialogue

Louis' and Ben's cases point to a central ambiguity related to the quest for answer entailed by their dialogic filtration work; namely, what actually constitutes an answer? The users' perceptions of this ranged from the idea held by the cardiologists that the sheer reading of a patient's entries somehow makes up a response, or at least a satisfactory reception, to the request by some patients that concrete clinical actions should be taken in order for them to feel that their entries had sparked a true reaction. In between these two extremes was a blurred terrain of different kinds of verbal or written answers that seemed to constitute relatively satisfactory answers for patients with low expectations and for others were so insufficient that they felt no response had really been given.

⁶ In the *medication list* feature patients could create an overview of their medication and enter information about doses, side effects, and date of prescription.

However, across this range of acceptable and unacceptable answers runs a common expectation among the patients, namely that of a particular kind of *responsible* receiver. The patients' primary concern was whether or not there would be one permanent contact person 'at the other end' of P-Record who would take their entire medical situation into consideration and be obliged to follow up and make things happen, which also links to the inherently easier task of addressing a specific or even well-known receiver. As Louis says:

"There has to be more consistency: that the doctor who is to use this system also is the one following you over the course of several years. Because being a heart patient is not like having a disease that stops right now. I won't be cured tomorrow and that part of the heart that doesn't function will never function again." (Final interview with Louis)

In short, without an explicitly responsive and responsible receiver at the other end it would simply not be meaningful to make the extra effort of using P-Record. On this measure, the system failed in most cases. First of all, it only seemed to reproduce the lack of coherency often associated with distributed care as it still left it up to the patients to try to bridge institutional gaps and address the appropriate receiver. And secondly, P-Record delegated greater responsibility to patients for keeping track of their condition and treatment without a clear (interactive) goal. The importance of writing to *someone* and receiving a *response* simply meant that patients did not support the assumption that users would write for their own sake—an assumption expressed by some clinicians and part of the design script, especially the logbook function. Even here the patients wrote with a receiver in mind and with the expectation that the clinicians would at least attend to the contents. As Ben put it:

"(When writing in the logbook) I had in mind that the hospital would see it, keep an eye on it. Or when I am called in (for consultation) then they would just have a look. Now afterwards I don't know how much they actually looked at it. The doctor I saw he was not interested in anything. So if you are to (implement it) then I would hope that they have a look and read it, just like your medical record." (Final interview with Ben)

By insisting on an interactive use practice, Ben and the other patients can be said to resist central presumptions and ideals in the self-care discourse that guides many e-health designs, including P-Record.

Concluding discussion

In the analysis I have showed how patients sought to fulfil their roles as information providers by conducting dialogic assessments of relevance. They shaped their entries as contributions to a dialogue in the anticipation of response. Although this dialogic filtration work performed by patients, to some extent, made the system work as a filter, it also posed crucial challenges and paradoxically carried the seeds of the system's failure. First, dialogic filtration work was not an easy task: shaping one's entries required certain skills and knowledge. The patients' entries must themselves be understood as responses—as continuations of a dialogue opened by the system. However, it was unclear who the 'sender' of the system was and thus the interlocutor one was in dialogue with. Patients solely had to draw on their experience with and knowledge about the infrastructure of care. Despite this being an explicit design ambition, the system in itself did not "*support patients' invisible work of bridging inter-institutional care*" (Andersen et al, 2011b). Second, undertaking dialogic filtration work entailed expectations of response. However, a vast difference between patients' and clinicians' perceptions of what constituted a satisfactory response became evident. The cardiologists, in particular, acted more as passive receivers than "*implied responders*"—the role which the patients "*casted them in*" (Linell, 2001:104). The patients could, by and large, be said to experience the clinicians' responsive attitudes as either resulting in a discontinuation of the dialogue or, in a single case, leading the dialogue in an unwanted direction. In either case, this ultimately made using the system pointless to the patients.

The differences in expectations and attitudes between patients and clinicians link back to their differing descriptions of P-Record as a filtration device. For clinicians, P-Record showed potential as a tool for *managing* a dialogue, with filtration of information serving this purpose. In contrast, patients seemed to perceive P-Record as *opening* a dialogue—whether this presented as either a hopeful expectation or a negative anticipation. This difference might be conceptualized as an overall difference in *communicative projects* (Linell, 2001:224) between patients and clinicians—or, in the terminology of Garfinkel, different "*interpretation schemes*" (1967:205). Designing and implementing e-health requires careful considerations about which communicative projects a certain system is to support and an awareness of potential conflict between these projects. In the case of P-Record, while the system performed fairly well as a filtration device allowing clinicians to manage the dialogue, for most patients it did *not* perform well as a means to reach a responsive and responsible receiver. From a design-oriented perspective, the case thereby points to a crucial need for unfolding, negotiating and adjusting communicative projects of various users. Importantly, communicative projects are not stable, but shaped by their

mediators (the filtration devices) just as they also shape the use of these. As dynamic socio-technical assemblages, users' experiences, communicative projects, and devices together make up the dynamic filters of e-health—dynamic, since the 'filter' is constantly being adjusted *'in the repeated iteration between (the filter) and the world, the expectation being revised each time'* (Maurer 2013:66). When designing filtration devices, a central challenge therefore lies in how to support this continuous adjustment of expectations.

While unfolding, negotiating and adjusting communicative projects of users of e-health is by no means an easy feat, I suggest that a recognition of and engagement with the dialogical properties of the filtration work involved in the use of e-health is at least a place to start. I propose that an 'analytical filtration device' combining dialogism and studies of invisible work can generate insights into the participatory role as information providers that patients are given with e-health and into the implications it has for both patients and professionals and ultimately for the organization of healthcare. Often framed as levellers of participation, e-health technologies—and other participatory devices (Marres 2012)—both entail and partly conceal substantial work by its users, as has also been pointed out by other studies. I suggest that filtration work is an important, but until now unrecognized, part of this invisible work of patient participation, and that inquiring deeper into what it means to be a participant can be done by unfolding its dialogic workings and implications. While dialogic filtration work is also part of face-to-face clinical encounters, the introduction of e-health seems to have the potential to complicate rather than to support this work, at least from a patient perspective, partly as processes of adjusting the filter—and the dialogue—are inhibited and/or concealed. This stresses the importance of also looking into how filtration work closely relates to the materiality of specific filtration devices—without ever being fully determined by it. In the case of P-Record, a rather ambiguous script meant that especially patients were poorly supported in their filtration work, with Ben as vivid example. Yet, a clearer script might have posed other challenges. Relations and practices of filtration (note the verb form) are the key here: if we think of filtration devices as 'filters in themselves' we overlook or even mask the skills, knowledge, and motivations that go into and result from making them work. Furthermore, looking at *filtration* illuminates how filters (as socio-technical practices) are not just transformative, but also generative: they create overflows, for instance (unmet) expectations. This seems inevitable, and when invoking 'filtration work' as an analytical tool in relation to e-health, it is important to not just treat the differing communicative projects and expectations resulting from and guiding the use of filtration devices as barriers to overcome in and by design. Rather, they point to and should be addressed through broader discussions about how modern healthcare can accommodate (itself to) patient participation, with all the work and overflows it implies. I suggest that STS-

scholars may contribute to such discussions by experimenting with and thereby learning about what ‘good filtration’ between patients and clinicians might entail. Moreover and as a conceptual and methodological addition to CSCW-studies of information work (e.g. Health & Luff 1996; Berg & Goorman), ‘experimenting with filtration’ may also bring forth new insights in other contexts—in healthcare and beyond—where the production and sharing of information undergoes (digital) formalization.

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Technologies and tactics of participation: how patients shape their engagement through e-health

Authors: Karen Dam Nielsen & Henriette Langstrup

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Abstract

'Patient participation' has become a key phrase in healthcare, penetrating the interrelated arenas of treatment, innovation, policy, and market. Often presented as participatory technologies, e-health materializes this participatory project. However, 'patient participation' comes with a conceptual vagueness, at times rendering it an all-too flexible political trope or platitude, and, in practice, resulting in unclear invitations to patients. We seek to open up the alluring yet troubling figure of patient participation, by inquiring into how patients in different ways enact participation. Based on close ethnographic engagement in a user test of the e-health system P-Record, we show how a group of heart patients shaped their participation along three lines of "tactics" (de Certeau 1984): 'activism', 'collaboration', and 'compliant citizenship'. Our argument is twofold. Firstly, we suggest that any invitation to participate carries the inherent paradox that, although certain ideas of participation may be materially embedded, e.g. in e-health or other 'participatory technologies', the enactment of participation cannot be foreseen. To participate is to creatively make do with the situation and technologies at hand, making participation normatively variable in practice (Marres 2012). Secondly, these normative variations can be understood as distinct, though interwoven, lines of tactics that bring about different expectations and, to different degrees, allow patients to handle ambiguous invitations to participate. We propose that recognition of the potential multitude of participatory tactics - and their respective implications and affordances - underscores the need for and may inform more precise invitations to patient participation that better allow for alignment of expectations.

Keywords e-health; patient participation; material participation; tactics

Introduction

[P-Record] empowers patients by making them active participants. [...] [It] puts patients in the driver's seat [...] [and makes the patient] an active contributor [...] [and] an active partner in his/her own care and not just a spectator.¹

Patient-centred e-health technologies carry a much-heralded invitation to patients to participate, here illustrated by a snippet of promotional material that introduces the e-health system, P-Record. Intended to facilitate new modes of patient involvement in care practices, e-health technologies can be understood as forms of "*material participation*" (Marres 2012) in healthcare. At large, they are born out of and materialize the paradigmatic project of furthering the engagement of patients and citizens in practices and politics of healthcare. Yet, in practice,

e-health has been shown to deliver quite different, and often problematic, outcomes than expected. P-Record, the e-health system featured in this article, is no exception.

As has been the case in other arenas of science, technology, and governance (Irwin 2006; Wynne 2007; Jasanoff 2003; Marres 2012), one can talk of “*a participatory turn*” in healthcare (Prainsack 2011) that cuts across an otherwise heterogeneous landscape of medicine, medical sociology, healthcare policy, and innovation. Within this landscape, both empirical and normative claims are made: patients *do* engage productively in healthcare and these forms of engagement *should* be acknowledged, applauded and furthered. Patients’ rights to and, not least, their resources for, active involvement in their own care and in the optimization of healthcare practices are tirelessly promoted – and increasingly by powerful institutions such as the state, the biomedical establishment, and industry (Regeringen 2013; Sundhedsstyrelsen et al 2012; KMD 2014). Concepts like ‘patient-centered’, ‘patient empowerment’, ‘patient involvement’, and ‘patient-driven’ have become everyday parlance; they penetrate and seemingly unite democratic ideals, neoliberal models for service delivery, chronic care paradigms, and design narratives in healthcare. Patient participation seems to have become a shared and almost ubiquitous strategy for improving healthcare in the twenty-first century.

With regards to the development of e-health technologies, ideals and methods of Participatory Design (Kensing & Blomberg 1998; Sjöberg & Timpka, 1998) often strengthen the participatory paradigm. Patients are *users* who should be actively involved throughout the ‘biographical life’ of a certain technology (Hyysalo 2010) – in design, implementation and use – and thus participate both in and beyond their own care. This way, e-health adds activities, discourses, and technologies to the participatory strategy – at once materializing and shaping this strategy. Indeed, e-health seems to represent a ‘technofication’ of the participatory strategy, which also shows in the popular as well as scholarly use of concepts like ‘patient 2.0’ and ‘e-patient’ (e.g. Danholt et al 2013; Felt et al 2009) to capture the emerging participatory patient role. To patients, the participatory technologies of e-health at large pose a bold invitation and a promise of becoming the central agents of healthcare activities; to researchers interested in opening up the troublesome figure ‘patient participation’ and its practical implications, these technologies make up prime objects of study.

Being a ubiquitous strategy, ‘patient participation’ is a conceptually challenging research object (Cornwall & Jewkes 1995; Gallivan et al 2012; Kvedar & Kibbe 2009). Several attempts at clarification have been made both theoretically and empirically (Cahill 1998; Eldh et al 2010; Thompson 2006; see also Corrigan & Tutton 2006) with definitions and taxonomies often entailing the establishment of criteria or even measurements for when participation can be said to be achieved, e.g. according to ‘levels of activity’ (Andersen 2010; see also Collins et al 2007 for an overview of approaches). However, in this paper we will refrain from adding to, what seems to us as, this Sisyphean work of trying to define and delimit patient participation, in principle. Rather, we depart from the observation that we are faced somehow, in contemporary Western societies, with a shared strategy of participation that is translated into a vast number of specific practices involving healthcare professionals, policy makers, designers, and patients every day, across our diverse healthcare systems. Our interest is to understand how specific

patients respond to the ‘technoficated’ strategy of participation and the accompanying role of ‘participatory patient’. The interesting question is not whether patients participate - they clearly do, as repeatedly stressed by medical sociologists (see for instance Strauss et al 1985; Oudshoorn & Pinch 2003) – but rather *how* patients participate when participation is what is expected from them. As did the early, empirically rich sociological accounts of ‘patient work’, we wish to explore participation as it is practiced – now in the context of a ‘participatory-minded’ healthcare system, and through devices and arrangements specifically made for instigating participation.

Applying the concept of *tactics* inspired by de Certeau (1984), we explore the creative ways in which patients in a user test of a patient-centred e-health system for ICD-patients² (P-Record) respond to the invitation to participate in research and in their own care. With tactics we want to suggest, that while carrying certain framings and conditions with it, the strategy of participation is also by definition open: to participate is to make use of the opportunities given, and patient participation must, therefore, be expected to be characterized by multivalency. Responses to the invitation may be shaped by a variety of preferences, concerns, and previous experiences, as well as by the materiality of the technology in question. Tactics also connote a way of manoeuvring in unclear territory, where local opportunities and challenges are handled *in situ*. Tactics may entail escaping the strategy of participating without leaving it, to paraphrase de Certeau (1984:xiii).

By placing these tactics and P-Record’s participatory capacity at the centre of analysis, we continue an STS-inspired orientation towards *material participation* (Marres 2011; 2012), which is to be understood not just as an analytical awareness of the situated and material aspects of participatory practices but as analysis of the way participation is explicitly inscribed in artefacts and enacted through the use of these. Our case reveals three situated tactics that we term *activism*, *collaboration*, and *compliant citizenship*. As shall be demonstrated, these tactics involved different sentiments and produced different versions of the ‘involved patient’. However, the patients’ enactments of participation also, to some extent, shared a reorientation. While P-Record invited patients to participate *both* in their own care for the good of their own empowerment and treatment *and* in research and design for the good of society, the latter ended up being most important to the patients. As a political terrain, the encounter between P-Record and patients’ participatory tactics seemed to support norms of engaging in collective projects more readily than norms of individual health projects.

In the following section, we outline our conceptual framework. We then briefly introduce our methods before moving on to the analysis, where we unfold the participatory practices facilitated by P-Record under the headings “*Designing participation*” and “*Enacting participation*”.

Theorizing participation

Past decades' political, technological, and organizational changes in Western healthcare all seem to have paved the way for patient participation as a ubiquitous norm and governance strategy (Moirera 2012; Prainsack 2011; May 2010). Scholars within the field of Science and Technology Studies have analyzed, from various vantage points, the ways in which patients actively engage in healthcare (Epstein 2007, Rose & Blume 2003), and increasingly are being mobilized as partners in healthcare activities from which they used to be excluded (Callon & Raberharisoa 2008; Langstrup 2010; van de Bovenkamp & Zuiderent-Jerak 2013). In some instances more explicitly than in others, these descriptions of patients' engagements become part of normative prescriptions of increased public participation for furthering a democratization of healthcare (Brown & Zavestoski 2004). As mentioned in the introduction, this is notably the case in the field of e-health, where the participatory paradigm is additionally fuelled by user-centered design methodologies (e.g. Clemensen et al 2007; Pilemalm & Timpka 2008).

Conceptualizing technologies of participation: Material participation

The field of Science and Technology Studies (STS) has been particularly invested in demonstrating and promoting public participation in science and technology, but has also, as Noortje Marres (2012) has noted, suffered an unpreparedness to critically analyse “*the rise to prominence of participatory approaches in these areas*” (p. ix; see also Irwin et al 2012). Yet, STS *do* offer analytical tools to deal with the role of technological arrangements in social practices (Latour 1992; Akrich 1992) – also those concerning participation (Oudshoorn & Pinch 2003) – and thus offer central resources for turning the attention to participation as an empirical phenomenon deliberately promoted and enacted through specific sociotechnical arrangements. In her study of public participation in environmental issues, Marres (2012) deals with what she terms ‘material participation’ by looking at the role of things in political participation. The invitation to participate may be stressed in discourse, as in current welfare-state policy jargon, but it may also be uttered more quietly and materially, inscribed into the devices that citizens are asked to use. As Marres points out: “*A wide range of initiatives aimed at fostering public participation are explicitly designed to locate participation in material practices*” (p. 2). In healthcare, e-health technologies are examples of this.

In light of this material participatory turn, the analytical goal becomes to “*note the normative variations among enactments of material participation*” (Marres 2012:2). Investigating actual use practices will reveal more nuanced stories about what material participation is and what it produces. Problems of participation – for instance the lack of specific responses when invited – may have less to do with resistance to participate and more to do with a mismatch between the institutional strategy and the realities and concerns of the people targeted (p. 11-12). The everyday situations at home, where people act with participatory technologies, are inherently ‘messy’: they involve a range of concerns, practices and devices that will influence how participation in this context is enacted (Pols 2012; Langstrup 2013). And

moreover, there may already be vivid participation of kinds that are unrecognized by the institutions that call for more participation (Marres 2012). In our case, looking at the normative variations in how material participation is enacted implies an attention to both the initial framing and the actual use of P-Record. As participatory devices, e-health technologies are currently politicized; that is, they are promoted as having certain normative capacities that make patients active in a way that is beneficial, first and foremost, for patients themselves, but also for ‘the greater good’ of the welfare state. In the case of P-Record, the designers and other protagonists discursively framed and materially inscribed the kinds of participation expected to arise from introducing P-Record into ICD-care. However, the norms invested in technologies do not translate unchanged, and the actual form(s) of participation facilitated by P-Record must necessarily be studied in, and as, practice.

Conceptualizing modes of participation: Tactics

Studies of how people in their everyday life deal with material arrangements inscribed with normative expectations can provide us with conceptual tools for exploring the multivalency of participatory practices and devices. Here we find the concept of ‘tactics’ (de Certeau 1984) useful. In his exploration of everyday life, de Certeau suggests that users of products, technologies, physical structures, media, and other aspects of ‘private life’ should be seen as actively engaged in *tactics* – the creative ‘making-do’ with arrangements that are given to them. Users’ tactics, he argues, are inherently a form of opposition against the strategies imposed by elites and decision-makers (de Certeau 1984). To use or consume is in no way passive, but rather a way to “*produce without capitalizing*” (p. xx). The strategies that de Certeau’s users ‘poach at’ are arguably more unambiguous structures of power than the ‘soft’ idiom of participatory healthcare that has grown out of exactly recognition of and an interest in capitalizing on the wisdom of users (see for instance von Hippel 2009 or Bason 2010). What de Certeau described as “the art of the weak” (1984:37), taking place in clandestine practices, has been recognized as central to legitimization and innovation in healthcare. Still, even in this amorphous strategy that has sought to co-opt resistance, the concept of tactics challenges us to look for the ever-arising manoeuvres that users will come up with when forced, called on, or invited to take part.

Our use of de Certeau’s concept of tactics is an attempt to approach ‘*a better and more sceptical understanding of the seemingly positive turn*’ (Wynne 2007:100) to participation in healthcare. Such scepticism has been articulated most clearly in relation to public participation in governance of science and technology (e.g. Delgado et al. 2010; Bogner 2011; Irwin et al. 2012; Wehling 2012), suggesting, for instance, that clear distinctions are needed between the invited or uninvited acts of participation, since the latter may easily be unrecognized, as participation is increasingly being institutionalized and professionalized by ‘participation entrepreneurs’ (Bogner 2011:511). In our case, we, indeed, did find ourselves in a ‘participation lab’, where ICD-patients were asked help explore P-Record’s potential as a tool for more

participatory care practices, with the first author acting as a ‘participation entrepreneur’, as she designed and conducted the user test.

Together, the notions of ‘material participation’ and ‘tactics’ provide an analytical framework for exploring how patients meet the invitation to participate inscribed in e-health. It allows us to recognize both the role of the technology as a facilitator of participation and the creative interpretations and enactments of participation by its users. Furthermore, it allows us to describe these enactments as distinct participatory modalities, which highlight the implications of the kind of ‘soft’ strategy that an invitation to participation is, and subsequently to reflect critically on invited participation, as it takes place in our case and in contemporary healthcare, more broadly. So from here, we set out to investigate the following questions: How does material participation unfold in the case of e-health for ICD-patients? Which tactics are used by patients; and, which norms and purposes are enacted, *vis a vis* the overall strategy of patient participation in healthcare?

Methods

The article is empirically based on the first author’s engagement in the design of P-Record with the user test as the pivotal event. The user test took place over the course of three months in the winter 2012-2013, as the culmination of a five-year-long Danish design research project, Co-constructing IT & Healthcare (CITH)³. It involved six ICD-patients, two cardiologists and two technicians from a specialized ICD-clinic at a university hospital, and two cardiologists from the out-patient heart clinic at a local hospital. Throughout the user test, the first author acted as facilitator, thereby taking an interventionist approach in the ethnographic fieldwork and, as mentioned, serving as a ‘participation entrepreneur’, as shall be demonstrated in the analysis. Patients were recruited by phone and subsequently given instructions of how to use P-Record in their homes. During the user test, patients used P-Record to prepare for three different appointments with the clinics: an in-clinic ICD follow-up, a remote ICD follow-up, and a consultation at the local hospital’s out-patient clinic. In between these appointments, all patients had telephone or e-mail contact with the facilitator regarding test activities or additional instruction. The empirical material consists of: 1) participant observation from test activities in home and clinic, documented by field notes and video recordings, 2) a total of 12 semi-structured interviews and a number of informal conversations with the participating patients, 3) two group interviews as well as informal conversations with the participating clinicians, 4) screen dumps of all entries made in P-Record, and 5) publications and project documents from the design phase.

In the following, we elaborate on the test activities and material outline of P-Record as well as the design rationale and process behind P-Record. Together, these ‘strategic elements’ made up the invitation to participate that patient-users were presented with and are, therefore, the natural starting point for our analysis.

Designing participation

P-Record was created and presented to its users as a participatory device: by its material layout and through practices of design and testing, it posed an invitation to participate and thus mediated an overall participatory strategy of modern healthcare. The invitation was characterized by: 1) framing participation as collaboration with clinicians in providing relevant information as well as self-managing, 2) putting technology at the centre as the enabler of participation, and 3) blurring the line between participation in research and participation in care. We will lay out these characteristics one by one.

Participation as collaboration

P-Record was born out of an ambition to handle several challenges in ICD-care. First, ICD-care faces a well-recognized challenge in contemporary healthcare: coordination of care distributed between various clinics and professionals. A central design ambition behind P-Record was, therefore, to “*enable patients to easier become information couriers*” and thus support patients in being collaborators who help “*bridge inter-institutional care*” (Andersen et al 2011b:5). Second, the use of remote monitoring of ICD’s for an increasing number of ICD-patients in Denmark means that most in-clinic ICD follow-ups are replaced with remote follow-ups. ‘Collaborative interpretation’ of ICD-data is, therefore, not an option: that is, clinicians’ interpretation of ICD-data cannot be linked with patients’ own interpretations of their condition (Andersen et al 2011a). In order to “*reintroduce the patients as active participants into the telemonitoring setup*” (p. e126), P-Record was designed to enable patients to provide written accounts of their own wellbeing and symptoms. Finally, part of the design ambition was to develop more efficient and cost-effective services, based on patient work. P-Record was to enable patients to “*take active part in collaboratively mak(ing) the situation more doable*” (Andersen et al 2011b:3-4) – or, put bluntly, contribute to making the most of the sparse time available. This was to be achieved by: 1) enabling patients to prepare for clinical encounters, and 2) supporting the patient as a self-manager who keeps track of his or her own condition and takes appropriate action, independently of the clinic.

In the design ambition for P-Record, participation was thus primarily framed as ‘collaboration’; however, ‘collaboration’ covered two different ways of being engaged. On the one hand, patients were to become “*reliable and valuable content provider(s)*” (Andersen & Moll 2010:1), producing information for clinicians that would inform medical decision-making, structure the clinical encounter, or even allow new services to emerge. The wish was to reposition the patient from merely a receiver of healthcare services to “*an equal actor and service provider*” (Andersen et al 2010:3). On the other hand, P-Record should enable patients to collaborate in a more indirect way by producing information for *themselves* that would enable them to manage their own situation, to a larger degree. Inscribed into P-record, these two

different versions of collaboration rendered the invitation to participate fundamentally ambiguous, as shall be elaborated on.

Technology as enabler of participation

By translating the ambition to involve patients as collaborators and information providers into a web application, the design project tapped into the vision of *“IT as a means for achieving shared care and involving patients as resources in their own treatment”* (Andersen 2010:151) – a vision that articulates a strong association between patient participation and e-health technologies.

P-Record contained a preparation form, a medication list, a logbook, an e-mail function, and a social network. In the user test, instructions started with the preparation form and medication list. The facilitator stressed these two features as the *“key functions”*⁴, and thereby framed P-Record as a tool to primarily communicate with clinics concerning specific appointments – a framing that was in line with the design ambition to support direct collaboration between patients and clinicians. Introducing the preparation form’s first and second part about general well-being, the facilitator stressed the patients’ own assessments: *“what the system invites to is that you yourself decide what you would normally tell [the clinicians] when you are there [at the clinic]”*, thereby framing the system as enabling patients to articulate their own perspectives. The preparation form’s third part contained predefined symptom categories – a formalization that was meant to ensure that patients provided ‘clinically useful information’; it was also presented as *“what the doctors have said they are interested in hearing about”*. The last part asked patients what they *‘would like to talk about at the meeting’* and was framed as giving them *‘the opportunity of setting the agenda’*. In sum, with the preparation form, patients were invited to provide information in return for receiving better answers; participation came across as a mutually beneficial deal built on information sharing.

Conversely, two other main features - the logbook and the social network – materialized the part of the design ambition that stressed patients’ role as self-managers. Indeed, the logbook exposed the ambiguity of P-Record’s participatory capacity: framed both as *“a resource for yourself”* and a tool to *“give [the clinicians] a little extra background”*, the logbook conflated whether one was taking part in a shared or an individual project, when used. Furthermore, the logbook clearly materialized the inherently open nature of an invitation to participate, as it was explicitly left up to the patients to decide *‘what feels relevant to write’*, as the facilitator put it. In contrast, the social network, where patients could share information, more unequivocally materialized the participatory paradigm’s stress on patient empowerment independent of contact with health professionals and, thus, extended the notion of participation even further than the logbook.

Entanglement of participation in research and care

In addition to the material design of P-Record, the entanglement of design and use also shaped the invitation to participate that patient-users were presented with. By being invited to a ‘rehearsal of the future’ (Halse et al 2010), patients were assigned a dual participatory role: they were simultaneously invited to participate in their own *treatment/care* and in *research* informing future care practices (Andersen 2010). These two ‘spheres’ of participation were deeply interwoven from the outset. Rooted in a Participatory Design tradition, the overall project actively involved future users throughout its iterative process, where patients and clinicians were invited to become “*co-designer[s]*” in a design process of “*collaborative prototyping*” and “*envisionment*” (Andersen 2010:151 – referring to Bødker & Grønbaek 1992). In practice, the participating patients took part in inscribing certain kinds of participation for future users (Andersen 2010:154).

In the user test, patients were not as directly involved in designing P-Record as in the earlier design process. Presented as knowledge background for deciding whether to implement P-Record as well as to inform future systems, the user test initially posed an invitation to contribute to the creation of knowledge and innovation; that is, to be part of a project ‘larger’ than one’s own care, yet with possible direct consequences for one’s own future care practices. Nevertheless, the user test constituted a participatory arrangement put in place with a dual and, at times, self-contradictory set of goals: to support the configuration of patients as users of the technology (Woolgar 1990) and at the same time study the ways in which patients responded to the invitation to participate. Managing this dual set of goals characterized the first author’s practice as participation entrepreneur, that is, her deliberate work as facilitator of making people into users of P-Record *and* research subjects. She, thus, had to handle one of the ‘paradoxes of participatory practices’ (Howcroft & Wilson 2003). On the one hand, she tried to keep an open approach and not dictate use, but rather sketch possible use practices while underscoring the experimental nature of the test. On the other hand, on-going guidance and reminders made the user test a laboratory-like situation, in which participation was nurtured in a specific way to enable research.

In sum, the overall project, and especially the design phase, built on a consistent and reflexive ambition to support patient participation in order to improve collaboration and ultimately create better care. However, when materially embedded in P-Record and enacted within the context of the user test, this ubiquitously ‘participatory project’ came to involve an ambiguous invitation to participate. Patients were presented with a soft structure, so to speak – one that by definition invited them to do things their own way, but nevertheless posed a prescription to *take part*. Moreover, signals were mixed regarding what they were to take part in – research or care practices, or at times just their ‘own projects’.

Enacting participation

Having presented the structuring invitation to participate, with P-Record as the device materializing this invitation and its inherent ambiguities, we now turn to how patients met the invitation and enacted participation. We thereby shift focus from the strategic to the tactical side of participation. Through exemplary cases, we unfold three participatory tactics. The three tactics cannot be delimited to their respective cases; to various extents, they interweave in all cases. However, we believe that each case exhibits one tactic in particular, and we foreground this tactic to be able to portrait its distinct features. In each case, we focus on situations from the user test that illustrate the dominant tactic. Background interviews provide a context for these situations.

‘Activism’

Anne is evaluating the social network function, browsing through the logbook of another patient, who has chosen to share this. She reads out loud: “Dizziness, anxiety, panic attacks”. She sighs. “If that’s caused by the medication then you should reassess it and give him something else. Those issues should make them find something else for that poor man. It’s his whole life!” I ask her if she would write this to him if she could. Yes, she would ask him to talk to the doctors about it: “You know, I can’t help thinking a bit further when he writes about such big issues”, she says, “You feel like saying something to him - that he shouldn’t put up with it, that he has to take it further”. (Evaluation of the system with Anne)

In the situation above we meet Anne, an experienced ICD-patient and research participant. She enacts what we term an *activist* participatory tactic: her attitude throughout the user test, as well as towards her situation at large, is characterized by pragmatism and low expectations, but also by an eagerness to experiment. She participates as a *representative* for other patients – with personal distance, but willingness to be actively involved, take on responsibility, and push for change.

Critical pioneering

During the recruitment for the user test, an alliance between Anne and the facilitator forms: they are both non-clinicians, critical of the existing communication practices, and pragmatic about the system’s potential; yet, they also share an activist’s desire to make things better. Thus and although posing an open invitation, the facilitator supports Anne’s attitude and enactment of participation by casting her in the role of critical participant in the project.

Anne has previously taken part in research projects. Most recently, she has signed up for a research project in the U.S. (independent of any Danish hospitals) that studies her specific and rare heart disease. This involves giving a DNA-sample. She follows the project’s website and

considers going to a scientific conference hosted by the project. Through engaging in this particular project, she, first of all, enacts hope for some future improvement on her own situation. However, with the prospects of a cure being very uncertain, her engagement can also be understood as a way of enacting the role of a ‘curious and interested’, resourceful, activist patient who raises her voice and tries to push the Danish healthcare sector towards more experimental practices. Anne is what we could call a ‘biomedical pioneer’ (see also Epstein 1996; Rose & Novas 2004).

In the user test, Anne explicitly acknowledges what takes place as going beyond normal practices; she treats the user test as an experiment and expects little from the concrete interactions, but remains motivated to test possible future practices. She takes an interest in the project itself, and asks about the project background, management, and results. Two general conditions seem to contribute to her experimental attitude, which is shared by patients with otherwise different tactics: the transparency in the project regarding technical problems and the participating clinicians’ inexperience. By being flawed, the system remains an open, experimental arena for participation. Additionally, all involved are ‘beginners’ in using the system, and, therefore, a kind of ‘shared pioneership’ is facilitated.

Insider and representative

For Anne, the idea of taking on ‘homework’ and producing information is not foreign. She already handles several tasks and devices related to her heart disease at home, such as manual transmission of ICD-data, self-monitoring, and medication management. On the one hand, she is content with these practices, as she feels confident and not in need for consulting clinicians due to her own professional background as a home-care assistant. On the other hand, she misses being followed more closely by a cardiologist, and feels that she has somehow slipped out of the system. She characterizes her own attitude as being more critical of medical authorities than other patients, linking this to general skills, professional qualifications, and being an ‘insider’ of the system.

Her pragmatic, yet experimental attitude also shows in her use of P-Record. Pessimistic about her own situation, but still curious to try out new practices, Anne raises a concern about the preparation form, although she has no expectations of receiving a response, as she has prior knowledge that the issue is clinically insolvable. During the following consultation, she actively engages in the use of P-Record, initially by referring to the issue she has raised, but then shifting focus from her own situation to assisting the clinician in manoeuvring in the system and commenting on his working conditions in the situation:

Mark has finished checking Anne’s ICD and only now turns to the screen to look at her entries in P-Record. Anne gets up from her assigned chair in the opposite corner of the room and stands behind Mark, looking at the screen over his shoulder. “Should I write a message?” Mark asks me (the facilitator). Anne jumps in: “You could do that if there was something to note”, she suggests. An error box occurs, preventing Mark from clicking on

the message function. “Apparently it wants you to shut down the logbook too”, Anne says, and while Mark is trying to open the message box, she continues: “You could just write hi”. Mark looks at me as to apologize for his confusion: due to lack of staff today, he is overloaded with work. “Actually I was to do an ablation (surgical procedure) and then this, right, and suddenly I also have to do another follow-up”, he says with frustration. “Who’s doing your ablation now then?” Anne asks in a concerned tone. (In-clinic follow-up with Anne and the technician, Mark)

The situation above demonstrates how Anne enacts participation in both research and her own care as an activist mediating patients and professionals: she establishes a position as both a ‘healthcare insider’ and ‘patient representative’.

This brings us back to the opening situation with Anne evaluating P-Record’s social network, which demonstrates her way of representing and caring for other patients first and foremost - in the user test and in general. Anne is engaged in patient organizations as a patient-to-patient advisor. Moreover, she follows two Facebook groups of heart patients. One is for Danish ICD-patients, and she primarily describes her use of this group as a way of educating herself as an advisor by staying updated on common concerns and new treatment options. She perceives herself as more ‘serious’ than most members of the group; she is annoyed by the purely social exchanges and rarely writes anything herself. In following the second group, an international patient group focused on sharing new knowledge regarding her specific heart disease, she is, to a larger degree, acting out of concern for her own situation. However, since Anne realizes that any future treatment advances probably will not be in time to benefit her, her engagement also seems to be driven by a motivation to bring about change for other patients and in the Danish healthcare system, at large.

As a participatory device, P-Record is but one of the tools with which Anne engages with these larger issues and collectives. Using P-Record to experiment and push for change beyond her own situation, Anne, first and foremost, seizes the invitation to take part in *research*. However, aware of the ‘politics’, hierarchies, and simply the working conditions in healthcare, she has no expectations of entering an equal collaboration: with a critical stance - and personal distance - she enacts an activist tactic. As a result, Anne seems better able to handle the ambiguity of the invitation and stay clear of disappointments than other patient-users. One of these others is Ben, who we will meet next.

‘Collaboration’

Like Anne, Ben is eager to enter a shared project of sparking change, but with higher expectations and a very different participatory tactic. Ben has had his ICD for eight years, but is, nevertheless, still trying to come to terms with its impact on his daily life. This includes having to navigate in a distributed care scheme that in his experience lacks coordination and fails to give him concurrent answers. With this background, Ben participates to become a partner, with high expectations of P-Record and, subsequently, experiencing a huge disappointment with the

outcome. His attitude is characterized by a willingness to take on responsibility, if it is shared. In other words, Ben seizes the invitation to collaborate in a direct manner and resists the parts of P-Record's script that imply being either solely an information provider or an independent self-manager.

Let's try something new!

Ben, first of all, describes his motivation for participating in the user test as a matter of always being ready to try to do things smarter:

I'm always in for something new, exploring new things. [...] And I think there's a challenge here. For instance, in elderly care where they use online tools to talk and so on. And what if you received a text message when you had to go to the doctor – it doesn't cost much and it's done automatically. These are cheap solutions. It annoys me when people don't show up – it's expensive labour when people [the staff] have to wait for those who don't show up. (First interview with Ben)

This way, Ben links his motivation to participate with his concern for the provision of welfare services and his interest in creating solutions. As such, he already sees himself as part of a broader societal collaboration. He positions himself as a responsible citizen who cares for the healthcare system; and, for him, becoming a participating patient and research subject through the user test is, first of all, an extension of this civic commitment.

During the user test, Ben actively engages in solving technical problems and proposes additions to the design, such as spelling control, automatic warnings, and document upload, and thereby acts as co-designer and project partner. In doing so, he seizes the invitation to participate in a transparent experiment, in which the facilitator and clinicians also tinker with the process, system, and practices, as they go along. Overall, Ben treats the user test as a collaboration, in which he participates with enthusiasm, initiative, and advocacy. At one point he tells the cardiologists at another hospital, where he works in a service function, about the project and tries to establish a contact between them and the facilitator. Likewise, concerned with how his perspective will be heard, he suggests a workshop where patients can discuss the system together with leading clinicians and the designers. Throughout the user test, he challenges the project's timeframe and does not readily accept having his partnership terminated as the project comes to an end.

Bridging the gap

In addition to societal concerns, Ben's motivation to participate in the user test seems to rest in the hope of improving the specific care practices that he is engaged in. From the beginning, he approaches the facilitator as someone who might help sort out the problems that he is currently

facing. These include technical issues with the telemedical setup, medical issues regarding his blood pressure, and lack of coordination between the local heart clinic and his GP. He, thereby, enrolls the facilitator in the infrastructure of his care, and research and care become fused into one practice. The way Ben initially uses P-Record illustrates this:

Before the first in-clinic follow-up, Ben writes a request for a 24-hour blood pressure monitor in P-Record, since he experiences variations that affect his ability to work. He also writes a message to me (the facilitator), with the contact details for a cardiologist at the local hospital to whom his GP has referred him regarding his blood pressure, but who has not yet called him in. At the in-clinic follow-up, he draws the cardiologist's attention to his writings and further presents her with the referral letter. She briefly tells him to take it up with the local hospital since it has nothing to do with the device follow-up. Afterwards, Ben is irritated and refers to the situation as typical: "What's needed is collaboration, and that's what I often miss". He repeats an earlier suggestion to enable upload of documents in P-Record and asks me if I can contact the local hospital and clear things out. (Preparation and in-clinic follow-up with Ben)

Firstly, Ben's call for collaboration related to his care is an expression of frustration with current practices, which he sees as characterized by deficient communication and coordination between various clinicians. The task of mending the gap by carrying information between clinics and pushing for action (for instance having a 24-hour blood pressure monitor) is not easy for him and does not lead to the results that he hopes for. Secondly, his call for collaboration also expresses his wish to take part - to be a partner and a responsible patient-citizen. Besides trying to make out and tie the ends in the care infrastructure, he takes on an active role in his own care by reading up on medications and measuring his pulse and blood pressure. However, Ben does not experience that this pays-off, that is, that his knowledge and data are sufficiently included or acknowledged in the medical decision-making. Being "*medically socialized*" (Pols 2013:5) does not necessarily lead to 'epistemic levelling', so to speak. P-Record's invitation to participate and promise of supporting him in 'bridging the gap', briefly sparked hope for immediate change. Yet, despite his efforts to respond to the invitation, nothing improves. In his first attempt, he targets the wrong receivers – the device cardiologist and the facilitator. In Ben's second attempt, with the preparation form for the consultation at the local hospital, the cardiologist responds with reservations towards Ben's request for a blood pressure measurement as well as to his question regarding an off-the-counter drug that he has done some research on.

In sum, Ben's collaborative tactic is, by and large, in line with P-Record's invitation to participate. It also reproduces at least one of the ambiguities of the invitation: Ben's use of P-Record cuts across research and care and, at times, adds to the obscurity already built into the user test. This does not, in itself, cause trouble. However, since Ben seizes the invitation to become a collaborator in *both* research and care, he is highly disappointed when the user test only brings forth the existing challenges of distributed care without facilitating immediate

change for him. Moreover, collaboration – whether research or care-related – turns out to involve less of an equal and mutually committing partnership than he expected.

‘Compliant citizenship’

In our last case, we illustrate a participatory tactic that, in its subtlety, might escape conceptualizations of patient participation underlining partnership and active engagement, like the ones informing the project behind P-Record, however sensitive to invisible forms of patient work they may be (e.g. Unruh & Pratt 2008).

Leo and I are waiting at the device clinic for his in-clinic follow-up. In the corridor we meet the project nurse who he knows from another research project and expresses a personal trust in; she is welcoming but also hasty. During the follow-up, the technician and cardiologist take their time to discuss the system. Leo is involved in the conversation, yet most of the time he remains a spectator. His reticent attitude is underscored by the way the technician – without much success – tries to involve Leo in speculating about the future potential of P-Record. The cardiologist thanks Leo for his efforts and, admittedly ironically, praises him for being “a good patient” as he has done his homework with P-Record. The visit ends with other hospital staff brusquely asking us to leave the room – we have occupied it for too long – and Leo making apologies. Despite the awkward closing, Leo is still up to completing the rest of his tasks in the user-test – with a little instruction and encouragement from my side. (Leo’s visit to the device clinic)

In this situation from the user test, we meet Leo. Most of all, he participates out of a sense of duty – towards the care scheme, society and fellow heart patients, and anchored in a general acceptance of authority. His attitude is characterized by a willingness to participate, if it can help others or calm his relatives, or as part of fulfilling a contract with the healthcare system. He tries to keep his engagement to a minimum – to just comply, and otherwise focus on something other than things related to his heart disease, be it care practices or research projects.

‘If it can help you’

When initially presented with P-Record and the user test, Leo is hesitant. He draws his own eligibility as a participant into doubt, calling himself ‘a rather banal case’ – he ‘has no problems or anything else to write about’. Although he ultimately agrees to participate, he continues to express doubts about the value of his participation – unsure if he ‘can contribute with anything’. In a very direct way, he responds to the invitation to participate as it is inscribed in P-Record: he equates the extent of his contribution with the extent to which he uses P-Record rather than his overall participation and deliberations in the project. Yet, he goes on participating by complying with the project protocol: he fills out preparation forms for follow-ups, calls the facilitator for instructions (as he wants to do it correctly), and shows up for extra

consultations at inconvenient hours. From the rationale that ‘*if one can help others*’, he seems to put aside the feeling of not being able to respond to the invitation to become an information provider and, instead, responds to the invitation to participate in a research project, despite its seemingly more obscure purpose (as assessed by him).

With reason: balancing duty and good sense

Leo has had his ICD for three years and been a heart patient for 10 years, starting with a heart attack. He was talked into getting the ICD by his wife and the cardiologist, and when asked if he is happy with it, he refers to the authority of the doctors: “*If they think it is good for me, then it is*”. His situation, today, is characterized by routine and stability. Describing himself as “*feeling alright*”, adding “*under the circumstances*”, Leo takes on a pragmatic, modest attitude when coping with his situation. Overall, Leo is content with the care he receives. In all of his years as a heart patient, he has had the same cardiologist at the local hospital, and his trust in the care scheme partly seems to rest on this continuity and the quality of their relationship. He does not ask a lot and is fine with “*not always being told everything*”. However, Leo actively takes on the job as information courier by routinely making sure to have tests done at the heart clinic before upcoming appointments with his GP and bringing the results with him to those appointments. He does so for sake of convenience as well as to spare the system of double work, not from anxiety: he trusts “*them*” to react if something is not right. He is likewise content with the remote monitoring setup: while he did not mind going to the clinic often, he feels safe and recognizes that this is easier for the clinicians. Besides attending consultations, doing ICD-transmissions, and managing medication, Leo spends as little energy as possible on his illness and treatment – focusing on it “*only makes you ill*”.

The way that Leo uses P-Record during the user test mirrors his general tactic as a patient. He fills out the preparation form, but his writings are sparse: unless “*there is really something to write about*”, writing “*serves no one*”, he explains. The little he writes is for the sake of the research project and, likewise, he agrees to the remaining test activities, including interviews, since we need it to “*become wiser*”. In the end, he evaluates the system in terms of its usability and overall meaningfulness: on both parameters it fails to be something for him. He also links this to being part of a generation who are not used to computers and the kind of interactions computers facilitate. Browsing through the social network, he expresses respect for some patients’ need to share, but has no interest in using this feature himself. Leo regards his illness as a private matter and does not take active part in any kind of patient networks, as he imagines that non-medical related activities will end in “*talk about the heart*”. However, as a typical example of the way he tries to find a balance between his sense of duty and his wish not to grant illness too much attention, he is a member of the heart association, but “*only gives some money*”.

The challenge of finding a *reasonable* way of being a patient who is embedded in the social structures of patient communities and society at large, also frames Leo’s participation in other research projects. Participation in these projects has been with varying success seen from his

perspective. One project at the heart clinic gave him access to a rehabilitation program, which he was very pleased with; another project at the device clinic provided increased personal contact and continuity thanks to a dedicated project nurse. But a third project, conducted by a pharmaceutical company, caused frustrations when neither his own data nor the overall research results were conveyed to him and he opted out. Leo is willing to help out, even when he does not immediately recognize the potential value, but there needs to be fairness. By taking on the task of providing information, for clinical or scientific purposes, he enters a reciprocal relationship. He participates in practices that he expects to be founded on an unspoken contract of reasonable exchange. While he seeks to comply with medical authority and contribute to a broader community, his motivation drops when the counterpart does not enact the same sense of decency.

Leo's participatory tactic as a compliant citizen allows him to respond to P-Record's ambiguous invitation to become a participant without subsequent disappointment. As he shifts orientation from responding to the invitation to become involved in his own care in a new way (as information provider or self-manager) to simply respond when called upon to 'help out', participation becomes meaningful. Thus, he becomes a user and participatory patient after all – but just for the occasion.

Concluding discussion

With our analysis of participatory practices in the user test of the e-health system P-Record, we have showed how patients in different ways may respond to the current 'technoficated' strategy of participation in healthcare, and, thus, become participatory patients when invited to. The patient-users of P-Record were faced with a rather ambiguous invitation - one that framed participation as collaboration in both a direct and indirect manner, and further obscured the purposes of participation by simultaneously inviting patients to take part in research and care. With this built-in ambiguity, P-Record – for better and for worse – materialized and mediated an overall ubiquitous participatory strategy in healthcare. This strategy proposes to serve a multitude of 'projects' and, per definition, involves a paradoxical prescription of taking part, leaving it relatively open how.

Becoming users of the participatory device, P-Record, thus involved dealing with ambiguity. As we have shown, the patients did so – with varying success – by employing different tactics. With an activist tactic, Anne responded to the invitation to participate in *research* first and foremost; from the onset, she handled the ambiguous invitation by focusing on a personally distanced 'project' with more abstract outcome criteria. While she endorsed the role as participatory patient and actively used the participatory device, she did so to give voice to and push for change for a larger community of patients, rather than to collaborate in (reconfiguring) her own care. Within this at once pragmatic and ambitious orientation, material participation through P-Record became meaningful despite failing to lead to the promised outcomes in care. Likewise, practicing a tactic as a compliant citizen allowed Leo to reorient

from his own care to a larger project. At first, the entanglement of research and care made Leo hesitant towards the invitations to participate: not finding it meaningful to become an information provider, he saw himself as an ineligible participant. However, Leo's attitude as a compliant citizen led him to answer to the invitation after all, but with what we could term a fragile engagement resting on balanced interpersonal relations only, which made him an unlikely long-term user of the specific participatory device. Ironically, P-Record's ambiguous invitation to participate proved most problematic for the patient-users who responded most directly to the invitation to become collaborators. Ben participated as a collaborator; but, this also meant that when P-Record did not deliver as hoped and promised, Ben had no alternative tactic to reside to, and accepting the invitation to become a participatory patient ended up in disappointment and great frustration. Finally it should be noted, that no patients opted for the (in theory, possible) tactic of using P-Record as a device for 'their own', independent self-management, the individualized version of participation as an invitation to keep away from healthcare resources, which at times surfaces in discourses of e-health (Petersson 2012).

Applying the concepts of 'material participation' and 'tactics', we have sought to cast a sceptical and empirically curious light on the ubiquitous strategy of patient participation in healthcare. Our analysis provides insights into the effects as well as limitations of the soft strategy of patient participation. P-Record was as a participatory device bound to carry ambiguity: it provided a script for participation, but also an open invitation to its users to engage, according to their individual preferences. What followed were indeed different normative variations over material participation in healthcare – unforeseeable, unruly, and entailing expectations that were not met. But in some cases, they also provided norms and purposes that – although they did not mirror those embedded in the invitation – made participation meaningful. In our cases we found that while the collective and societal benefits of participating in research fitted well with patients' tactics, patient participation in care practices through devices to support both collaborative information sharing and self-management made up a much more intangible and less-meaningful project. With an increasing number of e-health solutions being promoted as participatory devices and vehicles for patient-involving care practices, it seems fair to suggest that the invitations to participation that they carry along will need a need much sharper focus for patients to be able to recognize the project they are invited to. This may allow for better alignment of expectations – and for resistance – to take place. However, awareness that any invitation to participate inherently will bring about unforeseen answers and alternative 'projects' is, perhaps, even more crucial in a participatory-minded healthcare system that has set its mind on equipping and inviting patients in new ways.

Notes

- 1 Extract from brochures presenting the e-health system featured in this paper, retrieved from <http://www.cgi.dk/ehealthbox>, June 2013 and April 2014. The name P-Record is used here as a common denominator for the various versions of the system.

- 2 ICD-patients are patients who, due to an underlying heart condition, have been equipped with an advanced pacemaker: an implantable cardioverter defibrillator (ICD), which monitors the heart and, in case of life-threatening arrhythmia, provides shock therapy.
- 3 See www.cith.dk.
- 4 This and all other untagged quotes integrated in the text are direct quotes from the user-test (text boxes and users entries in the system; informational material; and transcripts of interviews, instructions and clinical encounters).

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A design rationale for aligning concerns in e-health

Authors: Tariq Andersen, Jørgen Bansler, Finn Kensing, Jonas Moll, Troels Mønsted, Karen Dam Nielsen, Olav Wendelboe Nielsen, Helen Høegh Petersen, and Jesper Hastrup Svendsen (authors listed in alphabetic order)

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Abstract

Background: Patient-centred e-health services are heralded as a means to achieve patient-empowerment, self-management, improved quality of care, and lower costs. However, much less attention is given to how such services should be designed in order to ensure the inclusion of patients as active users and co-producers of their own care.

Purpose: To present a conceptual framework for designing patient-centred e-health services.

Methods: Following a participatory design process, we developed an e-health service aimed at facilitating implantable cardioverter defibrillator (ICD) patients' self-monitoring and communication with clinicians. We tested prototypes of the service with patients and clinicians in real-life situations and gathered feedback to continue developing the service. Data were collected by means of qualitative interviews, participant observation, workshops with patients and clinicians, and design interventions. Subsequently, these data were analysed to identify the concerns and priorities of patients and clinicians. The analysis was informed by the insight from medical phenomenology that there often is a significant gap between the way illness is experienced by patients and the way in which clinicians conceptualise disease in biomedical terms.

Results: Patients' overriding goal is to come to terms with their changed situation, curb their anxiety, and re-establish a meaningful life. Clinicians, in contrast, focus on providing effective treatment in accordance with generally accepted medical standards. This divergence of concerns presents a fundamental challenge for designers of patient-centred e-health services. Based on our findings, we propose a coherent set of guidelines for aligning the concerns of patients with those of clinicians. Specifically, we propose that designers focus on (1) meaningfulness, (2) actionability and (3) organisational feasibility of concerns when designing patient-centred e-health services.

Conclusion: Designing patient-centred e-health services is a complex and challenging task because patients and clinicians bring different concerns to the table. Consequently, the alignment of concerns is a key prerequisite for a successful outcome, and a framework for accomplishing this is presented.

Keywords

Patient-centred e-health, medical phenomenology, participatory design, alignment of concerns

1. Introduction

The recent emergence of patient-centred e-health services, such as *telehomecare* and *personal health records (PHR)*, marks a new stage in the on-going development and rollout of healthcare IT. In contrast to previous systems, such as *hospital information systems* and *electronic medical records* which primarily targeted clinicians and hospital administrators, these new applications also seek to involve patients as active users.

There are great excitement and high hopes for patient-centred e-health services: they are expected to enable patient empowerment and self-management as well as improve quality and efficiency of care [1-3]. However, at present most of these benefits are largely hypothetical and the clinical effectiveness and cost-effectiveness of these solutions have not been demonstrated [4,5]. In addition, several authors warn that patient-centred e-health services may have detrimental effects on the patient-clinician¹ relationship and that they in some cases may force patients to take on tasks and responsibilities that they do not feel capable of dealing with [5-8].

Indeed, the inclusion of patients as users of e-health services introduces a whole new class of challenges for health informatics. Patients have different concerns and needs than physicians and other health professionals and these concerns and needs must be satisfactorily addressed if patient-centred e-health services are to be successful. However, it seems that researchers and designers, in general, do not truly understand the scope and complexity of this task.

To address this issue, we look into how patients' perceptions of illness differ from clinicians' and explore the implications for the design of patient-centred e-health services. In doing so, we draw on insights from medical phenomenology as well as on empirical insights from our own process of designing an e-health application for patients with chronic heart disease. We argue that *alignment of the concerns of patients with those of clinicians* is a prerequisite for the successful design and implementation of patient-centred e-health services. This does not imply that patients and clinicians need to have identical perspectives on illness and treatment, but rather that their respective concerns and needs must be recognized and reconciled. Otherwise, there is a high risk that the new e-health service will not support the actual practice and, thus, that patients or clinicians will be reluctant to adopt the service. We end the paper by presenting a design rationale that focuses on how such alignment can be achieved and subsequently discuss its methodological and research related implications.

¹ Overall, we use the term 'clinicians' as common designator for physicians and other health professionals - in ICD-care, lab technicians are a particularly important group. However, when referring to theoretical work or other studies, we use the terms applied in these - often 'physicians', which used as a more specific designation.

2. Background

Early research and development of healthcare IT focused on so-called hospital information systems (HIS), which were limited to single wards or hospitals. Users consisted mainly of administrators, physicians and other health professionals [9,10]. With the emergence of health informatics in the 1990s, the scope broadened to include systems spanning multiple hospitals, global information infrastructures, and strategic information management [11]. But the users were still primarily hospital staff and administrators.

However, over the last decade, patients have come to play an increasingly important role in their own treatment and care, and under the umbrella of *e-health* researchers and designers have begun to extend the network of users to include patients (and their relatives) [12]. Examples of e-health services that target patients include patient-provider portals (e-visit and e-booking), telehomecare platforms [2] and PHRs [13,14]. Furthermore, there is currently a rapid growth in consumer-oriented health websites, mobile applications, and social software that enable patients to engage in self-management and exchange experiences and advices to better cope with day-to-day personal health issues [15]. It is still too early to tell where this new technological trend leads, but it is likely to have an important impact on the future of healthcare [5,8,13].

2.1. Patient participation in e-health

It is generally expected that patient-centred e-health services will facilitate patient participation, self-management, and empowerment [4,5]. It is suggested that such services can become a “supplement to existing relationships and forms of care” [5], improving behavioural outcomes through tailored communication and increased interactivity [7]. It is also suggested, that e-health has the potential for creating “favourable circumstances for improvements or strengthening of patient participation” [5]. For example, PHR’s and various health sites may make patients better informed and empowered [14] and thereby possibly better equipped for “self-management” [1] and “shared decision-making” [7]. E-health can also function as a lever for engaging health professionals in working together with patients and stimulate discourses on “patient centred care” [16].

However, early experiences with patient-centred e-health services also point to many challenges and unintended consequences that should be taken into consideration in the design of future applications and services. For instance, Dedding et al. [5] warn that these services may “disturb” patient-clinician relations and lead to more “sick work” for the patients. Therefore, they advise that “more attention should be paid to the redistribution of tasks and responsibility to patients.” Other unintended consequences may be added responsibilities and extra costs for providers [5] – costs that are often not covered by existing reimbursement models. Clinicians may also feel that their professional practice is threatened or undermined by the new technologies. For example, Chen et al. [6] highlight the challenges of e-visits, where patients and physicians

communicate online, and question whether physicians can build trust and engage in diagnosis without being able to interview, observe, and examine the patient in person. Similarly, Oudshoorn [8] describes how health professionals working with telecare need to learn new skills such as how to create “intimacy at a distance.” She also describes how telecare can have the unintended consequence of shifting responsibility onto patients so that self-care is forced upon them whether they like it or not. In a similar vein, Langstrup [17] describes the negative effects of telehomecare and how “family members become, willingly or unwillingly, parts of the chronic care infrastructure.”

So, delivering on the promise of patient-centred e-health requires an in-depth understanding of not only the technology but also the needs and concerns of the relevant actors, in particular clinicians and patients.

2.2. Divergent meanings of illness and disease

We suggest that an understanding of the fundamental difference between the perspectives and goals of patients and clinicians is key to successful design of e-health services. As S. Kay Toombs [18] has pointed out in her seminal book on the meaning of illness, there is a “decisive gap” between the way illness is experienced by the patient and the way in which physicians conceptualize disease in biomedical terms such as symptoms, diagnoses, pathology, treatment, and prognosis. “Consequently, rather than representing a shared ‘reality’ between them, illness represents in effect two quite distinct ‘realities’” [18]. Patients experience *illness* as a unique, personal event that transforms their bodily awareness and disrupts their everyday practices, roles and relationships with others [19,20]. Physicians understand *disease* as an entity in itself, a biological phenomenon that can be categorized as an instance of a known type, for instance as a particular case of “diabetes” or “ischemic heart disease,” and treated according to scientifically tested procedures [18,21]. This crucial difference is rarely acknowledged in the literature on e-health.

A reason for the apparent lack of attention to the gap between the perceptions of patients and physicians may be that it is obscured by the migration of scientific and technical medical terms, such as “congestive heart failure” and “pacemaker,” into ordinary, everyday language. The use of common terms suggests that physician and patient are talking about the same things, but as Hunter [22] has emphasized, “often only the physical signs and their diagnostic labels are the same; the understanding and the concerns are entirely different” (p. 14). In fact, the difference in perspectives is typically so deep-seated that it results in a “systematic distortion” of meaning in the patient-physician encounter [23]. The reason is that the difference is “grounded in the fundamental distinction between the lived experience of illness and its conceptualization as a disease state” [18] and thus goes far beyond differing levels of knowledge about illness and disease (with the physician being regarded as the most knowledgeable).

Firstly, physicians and patients focus on different aspects of illness. Patients encounter their illness as an immediate lived experience. It manifests itself as pain or other physical problems that disrupt their normal functioning and demand their attention. The categories patients use to make sense of it are “primarily concerned with everyday life and functioning” and often imbued with social and cultural meanings (p. 12). Serious illness, and in particular serious chronic illness, does not just affect the body. It can affect one’s whole life, one’s relationships with others, and how one sees oneself [24]. Patients suffer because their illness constrains their agency and because it creates anxiety and fear, but they also suffer because “they feel isolated from others, because they feel alone” [25]. In contrast, physicians are trained to “see” the patient’s illness within a prescribed conceptual framework (the biomedical model of medicine), as a typical example of a disease. Physicians conceptualise the illness in terms of abstract scientific constructs and in doing so primarily focus on “objective facts” such as physical signs, clinical findings, and laboratory data [18,21].

Secondly, physicians and patients are engaged in different “projects” and, as a consequence, have different criteria of relevance. The goal of physicians is to diagnose the patient’s condition (i.e. to fit the particular case with disease taxonomies) and provide reliable and effective treatment in accordance with accepted practice standards, clinical guidelines, protocols, and so forth [21]. On the surface, this goal seems to match the patient’s needs. However, as Toombs [18] has stressed, “the patient’s goals relate to the qualitative immediacy of his or her illness. They represent an attempt to integrate the experience into daily life.” (p. 18). The overriding goal of patients is to come to terms with their changed situation and develop effective coping strategies that allow them to curb their anxiety and re-establish a meaningful life [19,20,24]. One consequence of these differences in priorities is that patients and physicians disagree on what is relevant and what is not: “Since the ‘problem at hand’ is defined differently by patient and physician, according to goals that relate to their separate worlds, they do not share a system of relevance with respect to these goals.” [18]

Table 1 – Divergent concerns of patients and physicians (based on [18,23])			
	Perspective	Focus	Goal
Patients	Experience illness as a unique, personal event	Focus on everyday life and functioning where illness constrains the patient’s agency	Seek explanation and cure; develop coping strategies; manage fundamental fear of death
Physicians	Trained to “see” illness within a biomedical model of medicine	Focus on objective facts such as physical signs, clinical findings and laboratory data	Seek diagnosis, treatment and prognosis

In other words, physicians and patients generally have very different concerns about treatment options and priorities, medication side effects, symptom management, impact on daily life and relationships, identity and self-esteem, course of the disease, fear of death, and so forth. Patients with chronic diseases may, for instance, choose to “preserve aspects of their identity or habitus at the cost of symptom management” [20].

The fact that physicians and patients focus on different aspects of illness and that they often have starkly divergent concerns and priorities regarding treatment and “disease management” has important implications for the design of patient-centred e-health services, as we show and discuss through our empirical cases.

As a final remark, it should be noted that both patients and physicians, of course, have different needs and concerns. Differences in background, current life situation and physical and mental condition cause some variance with regard to patients’ ability and motivation to use health information and partake in own care [13, 14, 15, 16]. Likewise, because of pronounced professional specialization, physicians are often concerned with different biomedical indicators. Furthermore, it is increasingly recognized that physicians, when applying clinical guidelines, include the patient’s lived experience [11, 16]. Thus, what is presented above is admittedly an exaggerated dichotomy between the perspectives of patients and clinicians. Nevertheless, we believe it to be a useful analytical lens for opening up the challenges of designing e-health services that target both patients and clinicians.

3. Methodology

With this section, we describe the setting in which we performed the study, the overall research approach, and how we collected and analysed the empirical data. Also, we briefly describe the prototype of an e-health application that we developed, the use and evaluation of which are discussed in the following sections.

3.1. The setting

The study presented here is part of the research project *Co-Constructing IT and Healthcare (CITH)*² carried out by an interdisciplinary group of cardiologists, computer scientists, and sociologists. We focus on the treatment and care for chronic heart failure patients and on what it takes to obtain better-informed patients and clinicians and to support them in periods between

² See www.cith.dk for details.

visits at clinics. For this, we developed an innovative e-health service³ for ICD patients. Many heart failure patients at risk of sudden cardiac arrest due to ventricular fibrillation will have an implantable cardioverter defibrillator (ICD). This device is an advanced pacemaker designed and individually programmed to pace and, if needed, to give an electric shock to restore the heart's normal rhythm. The device also records data about arrhythmic events and related parameters with the purpose of monitoring the patient's condition in order for cardiologists to decide if particular interventions are needed.

The care for ICD patients involves multiple actors, who are part of a distributed and heterogeneous network. However, here we focus only on patients, relatives, lab technicians, and cardiologists. The main part of ICD care takes place in three settings: a university hospital's heart centre, patients' homes, and local hospitals. Implantation and device follow-ups are conducted at the heart centre. Currently, the majority of ICD patients are enrolled in remote monitoring. This means that ICD data are sent from patients' homes to the heart centre every three months, or when an arrhythmic event has happened.

Further, patients have to visit the heart centre once every second year for an in-clinic device follow-up. Whether it is an in-clinic or a remote follow-up, a lab technician and a cardiologist interpret the data. Sometimes they need to consult the patient's electronic medical record, a special ICD paper record, or ask the patient for more information in order to evaluate the patient's condition. When problems are detected, the patient is either referred to the local hospital if adjustments of medication is needed, or called in to have the device adjusted. Most patients are briefly informed that everything looks fine and told when to come in next time. Regular medication management is also part of the lifelong treatment of ICD patients, and every three to twelve months patients go for ambulatory visits at their local hospital for this purpose.

3.2. Research approach

Authors increasingly suggest to engage users in the design of e-health services [26,27] and participatory design has proven instrumental for this purpose [28,29]. Following this tradition, we have applied an explorative, experimental, and evaluative strategy within an overall iterative and participatory approach. *Participatory design* [30] entails that prospective users work with designers for the combined purpose of having a say and engaging in mutual learning with designers [31]. Clinicians, ICD patients, and relatives have participated actively in defining the aim of the project as well as in analyses, design, and evaluation. In total more than 50 patients and relatives and more than 15 clinicians have participated.

³ By e-health service we refer to both the IT application and the associated new ways of organizing treatment and care.

We began by *exploring* existing practices at home and in clinics. Then we *experimented* with versions (seven) of a prototype of a PHR (myRecord) and with a set of (re-)designed services supporting the work of clinicians, patients, and relatives. Based on such experiments, we adjusted the prototype, the tasks, and the roles, but we also learned about new issues in the current practices, which then informed the next round of design activities. In this way, we deliberately *iterated* between analysis and design. Initially, the experiments were conducted in isolation from the daily practices of patients, relatives, and clinicians, but through the iterations the prototype matured enough for us to cautiously try it out in the real life practices of patients and clinicians.

3.3. myRecord

We designed a PHR (myRecord) as an add-on to the existing telemonitoring system which have already replaced most of the in-clinic device follow-ups and is appreciated by clinicians and most patients [32]. myRecord was designed to empower patients who are willing and capable of taking more responsibility for their own care.

myRecord offered several features. In this paper, we focus on the features that support preparation for remote follow-ups and in-clinic consultations. As part of the preparation, patients were prompted to complete a questionnaire prior to a consultation. This meant updating and confirming their medication list and using their own vocabulary to pose questions about experienced problems or concerns. Further, patients were asked to report on their health status ticking off symptom categories based on the New York Heart Association's classification scheme, e.g. shortness of breath, chest pain or fatigue, and in which situations such symptoms occur. myRecord also featured a logbook to mark symptoms and keep a disease related diary. Other features included a calendar to keep track of appointments, easy access to guidelines, information on potential harmful interactions between prescribed medications, and a network feature to allow for interactions between patients [29].

3.4. Data collection and analysis

The CITH project lasted from 2008 to 2013, and we produced data throughout the project using primarily qualitative interviews and observations, collection of artefacts and documents. Interviews and observations took place in patients' homes as well as at the clinics. For a start, the purpose was to develop an overall understanding of who was involved in which types of activities and for which purposes. Later on, more detailed interviews and observations focused on specific treatment and care activities (including self-care) seen from the perspectives of the various actors. Interviews and observations were documented and selected parts were transcribed. This included noticing the ways in which patient and physicians organise and use documents and artefacts, allowing us to develop in-depth understandings of current practices. Data were also collected from workshops, prototyping and design interventions [See Bratteteig

et al. and Brandt et al. in 30]. The final evaluation was conducted as a user test [29] with patients and clinicians performing several pre-determined tasks, while being observed by a researcher who had not taken part in the design activities. Also, both patients and clinicians were interviewed about their use experiences.

In the data analysis, we followed an interpretive approach [33-35], iterating between understanding the whole and its parts and going over the raw material many times until we were able to form a coherent and solid interpretation of the subject matter. First, we coded the material, labelling emerging analytical themes. Secondly, we grouped and consolidated these themes into more general concepts. Based on these concepts, we chose four exemplary cases that we believe illustrate the concepts and their implications, in sum showing how the *divergent meanings of illness and disease* play out in situations of designing and evaluating IT support for active patient participation in e-health.

4. Results

This section presents our analysis, which our proposed design rationale builds upon. Leading up to the formulation of the design rationale, we illustrate our analytical insights through four empirical cases. Our goal is to illustrate how the differences that underpin the understanding and conceptualisation of symptoms and disease among patients and health professionals come to signify patient-clinician encounters and thus the use of e-health. There is a progression with each case, starting from a relatively simple example of a contradictory patient-clinician relation to the final case where the relational aspects are more entangled. For each case, we discuss how it illustrates a key challenge in the process of aligning concerns.

4.1. Case #1 – What is a meaningful concern?

With this case, we bring forth the difference in how illness is experienced by patients and how clinicians conceptualise disease and, furthermore, how this difference comes to designate what is perceived as important and meaningful to communication about by each part.

Louis is 51 years of age and has had his ICD for only a year after suffering a sudden heart attack. In his case, the experiences of becoming a heart patient and an ICD patient melt into each other. Louis suffers from various symptoms related to the heart disease itself, the device and the medication, as well as recovering from the heart attack. Besides this, Louis feels anxious and depressed, which he ascribes partly to the trauma of experiencing his own mortality, partly to the lack of continuity of care and the lack of coherence of the information he receives from health professionals and institutions.

Because of this, Louis is enthusiastic about the prospect for new ways and means of communicating with clinicians and engages very actively in the use of myRecord. He makes

several notes on symptoms with the logbook feature (ranging from feeling tired, loss of breath, swollen legs, anxiety, and impotence) and is eager to utilize the preparation module prior to his upcoming medical follow-up. Besides this, he explores the network feature to connect and share experiences with other patients. He praises the potential of myRecord and explicitly links his positive assessment of its value to his position as a new patient with a great need to feel secure and “in control” and to be able to raise urgent questions and seek continual professional guidance.

Having completed the preparation via myRecord, where he has written an extensive prose text about his symptoms and concerns, Louis has high expectations for the upcoming consultation at the clinic. However, afterwards he is greatly disappointed, as he did not feel that the clinician responded to all the concrete concerns he had raised nor attended to his situation at large: *“I was prepared for the consultation. And that thing regarding vitamin D, he didn’t mention it. He didn’t say anything to me. And regarding the legs, it was me who insisted, insisted, insisted [...] So, I was disappointed with the consultation, really.”*⁴

The cardiologist on the other hand felt that he was able to react to the patient’s *primary* concern (which he perceived to be the experience of dizziness and loss of breath and which he linked to a possible adjustment of medication) and then leave the rest unspoken, since it was not something for him to act on: *“Because he was allowed to write about it and he had made that list, I could just say to him; ‘I can see you’ve written something about this and that. This is the main thing for you,’ and we could then go straight to that topic without having to start all over. So, I think it’s a good way to manage the contact.”*⁵

The cardiologist further indicates that he thinks the very act by Louis of writing down his concerns would make him feel better and that Louis would further “feel heard” by knowing that the cardiologist had read through his preparation. This case illustrates how the clinician and patient have conflicting perspectives on 1) which concerns are meaningful in the sense of important and relevant for the consultation, and 2) what constitutes proper (re)action. The cardiologist perceives his role as to manage the consultation in the most productive and meaningful way, which for the cardiologist is to ensure that *his* most important concerns are attended to. Besides this, he acts as a passive listener through myRecord as an act that he believes will indirectly satisfy the patient. The patient, however, feels quite the contrary and finds much of the follow-up meaningless, stating that in order to be meaningful to him his efforts must result in a “real” (re)action at “the other end.”

4 Final interview with Louis, February 2013

5 Final interview with cardiologist, local hospital, February 2013

4.2. Case #2 – Is action possible at all?

With this case, we take the matter of proper reaction a bit further by illustrating the second challenge that plays an important part in the process of aligning concerns. Namely, that it is not enough for a concern to be meaningful. The concern needs to be *actionable* as well; that is, the relevant party should be able to take action.

Ann, an experienced ICD patient, is eager to test new means of communication in the hope of improving her life with an ICD. Her case illustrates that even when an issue is in principle perceived as relevant and topical by both the patient and the clinician, the lack of ability to *act* on this issue means that her concern cannot be aligned with clinicians' concerns and communicating about it through myRecord proves futile.

Ann is preparing for remote control of her ICD device by filling out the preparation form. When asked about her general well-being, she states that she *"is doing fine"*. When moving on to describe events and symptoms she writes: *"Neck-vein nuisance caused by electrodes and in some periods swelling, scar tissue?"*⁶ This entry refers to her persistent experience of pain in her right shoulder and neck caused by the ICD device pressing on a vein – a concern she has raised several times before. After the remote follow-up the lab technician who has read Ann's preparation form and consulted the device data responds that if the symptoms get any worse, she should call them.

When interviewed about the correspondence, Ann explains that she appreciates the lab technician's response but also states that it would not make sense for her to take it up again this way. The receiver is unable to take clinical action since it has already been established that re-positioning the device is too risky. Communication does not solve this problem. It could be argued that the concern raised by Ann is actionable in some "lesser" sense; the lab technician's response *is* an act – perhaps an act of care – and he feels he has acted in the sense of reacting with an instructive message: "call if it gets worse." But although Ann appreciates this reaction as a caring gesture, from her perspective it was not a meaningful exchange since it did not really entail action. In this case, myRecord did not align concerns as the concern raised by the patient was not actionable. It is possible to think of ways and situations in which an e-health service can *make* action possible, however, some issues will remain outside the scope and problem-solving potential of e-health.

6 Ann's entries in myRecord's Preparation Form, November 2012

4.3. Case #3 – Who can act?

This third case illustrates another variant of actionability. It shows how a concern raised by a patient is *in principle* clinically actionable; however, the ability to act rests with another clinician than the receiving clinician.

In a distributed care scheme clinical concerns are formally, and often also practically, distributed. This means that even if a certain concern of a patient may be of great clinical relevance (e.g. critical side-effects of medication) it will only be relevant for *certain* clinicians. When patients then write questions and state concerns in an e-health service like myRecord, where a certain clinician is the receiver, the patient must be able to assess what is relevant to whom or the e-health service must provide help. In other words, the patient must at some level understand the infrastructure of the distributed care scheme, or the e-health service should indicate or assist in this.

The participant Ben is preparing for the upcoming in-clinic device follow-up at his heart centre by filling out the step-by-step preparation form in myRecord. When he reaches the section where he can state his most important questions for the clinician, he writes that he is very concerned with his blood pressure because he finds himself increasingly exhausted when performing his daily tasks at work. Eager to find a solution so that he can keep working, Ben asks to have his blood pressure monitored over the course of a day at work.

During the consultation at the outpatient clinic, the lab technician and the cardiologist quickly browse through Ben's preparation form on their computer screen while they ask him about his general well-being, his medication and specific symptoms related to the ICD. Ben then asks about the possibility of having his blood pressure monitored and brings forth a referral letter for a local hospital, which he has received from his general practitioner. The cardiologist briefly answers that it is not something she can get into, and that he will have to take it up with the local hospital.

Afterwards Ben describes how he was *“disappointed about the fact that they hadn't read through it carefully. It just goes helter-skelter, you know. [...] Then it's just ridiculous to write about it (his concerns)”*⁷. Now that Ben with great effort had prepared so well using myRecord, he expected the clinicians to be prepared too and address his concerns. But he felt that the clinicians had not prepared properly and that their lack of interest and action in relation to his concern about his blood pressure made his preparation meaningless. The cardiologist on the other hand, stated how she, while being with the patient, was able to *“browse through what he*

⁷ Final interview with Ben, February 2013

had written”, and that the preparation form “*worked well*”.⁸ The cardiologist was not bothered by the fact that she was presented with a concern of the patient that she was not able to act on for organisational reasons. Rather, she found it useful to be able to quickly browse through the patient’s concerns and screen out those she did not have to pay attention to.

With this case, we show how the concern raised was both *meaningful* to the patient and the clinician and in fact also clinically *actionable*, but it was not *organisationally feasible*. One party, the cardiologist, is pleased with myRecord and not bothered by being confronted with a concern that she is not able to take action on. The patient, on the hand, finds the encounter demoralising and disappointing due to what he perceived as an unsatisfactory “absence of action.”

The case thus illustrates how some patients are neither able to assess what could become a concern for *certain* clinicians nor will settle for the kind of brief response they subsequently may receive. For Ben, using this version of myRecord entailed great disappointment and led him to lose motivation for further use. This supports our claim that motivation for use rests on the existence of aligned concerns and of the e-health service’s ability to support these. In this case it fails to do so as it fails to account, or compensate, for the distribution of care by facilitating a ‘match’ between the concern of the patient and the concerns of the clinician in question.

4.4. Case #4 – Alignment of concerns with myRecord

While the three previous cases illustrate how myRecord was unsuccessful in supporting meaningful patient participation in some situations, the following case shows how other features of myRecord used in other situations provided for enhanced collaboration. In remote monitoring, patients are excluded from engaging with clinicians and both parties rely primarily on the data recorded by the ICD device. Patients can no longer ask questions and raise concerns, for instance regarding potentially relevant symptoms, in the time between the in-clinic follow-ups.

In design interventions with different versions of myRecord, we experimented with ways to fulfil the needs of both patients and clinicians by enabling patients to supplement transmissions of ICD data with their own experiences and by enabling lab technicians and cardiologists to respond in more effective ways.

⁸ Final interview with cardiologist, heart centre, February 2013

Consider the case of Irene who is 57 years of age. Irene was born with a congenital heart defect and has therefore been undergoing chronic care since an early age. The implantation of an ICD in 2005 has added to her anxiety, particularly because of inappropriate shocks (erroneous and severe ICD treatment) and her continuous experiences of arrhythmia. Irene feels that her health is “fragile”, as she says, and she has lately seen a psychologist, which has improved her well-being. During a design intervention of a remote follow-up with myRecord, Irene transmits her ICD data as usual from home, but this time she also uses myRecord where she answers the question “how are you feeling” by writing:

*“Up and down – I’ve experienced being dizzy several times and have had the same feelings as when I got atrial fibrillation [irregular heart beat] in 2008 [...] When the feeling arises, it makes me feel quite insecure, partly because I get dizzy, partly because I’m afraid of what it is.”*⁹ Irene approves her medication list, selects the appropriate medical categories, writes about her worries, and enters the specific dates and times where she has experienced dizziness and symptoms like atrial fibrillation: *“Registered episodes have been: 01.10, 11.10, 31.10, 05.11 (at 8.40 and approx. 12.15 to 13.00).”*¹⁰

The following morning at the heart centre, the lab technician reviews the transmitted ICD data and concludes that there have been no therapies and that no events are recorded. However, when she consults myRecord and reviews Irene’s writings and medication list, the lab technician decides to re-visit the recorded ICD data and the device settings. The lab technician concludes that the device is set up appropriately and decides to continue with her standard procedure and send the standard letter to Irene affirming that “the system is fine.” However, provided with the possibility of easily dictating an individual reply to patients in myRecord, the lab technician decides to take action and comfort Irene by explaining what the data and settings tell her:

*“Hi Irene, it’s the lab technician at the heart centre [...] I can understand that you feel uncomfortable and I have therefore checked the episodes you are mentioning. But the device has not recorded atrial fibrillation. So, when nothing is registered in the zones that we’ve set it up to monitor, I can assure you that the atrial fibrillation is well controlled and that you do not enter any critical zones [...] so, it’s really great that it works well with your medication [...]”*¹¹

This illustrates how myRecord supported Irene in raising concerns in a format that proved useful when the lab technician in turn was enabled to reassure Irene that the device was configured correctly. The symptoms (concerns) described by Irene were of particular interest to

9 Entry in myRecord, November 2010

10 Entry in myRecord, November 2010

11 Lab technician’s reply in myRecord, November 2010

the clinician in the telemonitoring process (device settings need to be configured in correspondence with symptom experiences). Hence, it enabled the lab technician to decide on proper action with improved confidence, improving her decision-making in remote monitoring. Moreover, the possibility provided by myRecord of easily making a voice-dictated and individualised reply (automatically transcribed), enabled the lab technician to accommodate the concern of the patient. In the language of e-health, myRecord supplemented the existing form of remote follow-ups and created favourable circumstances for active patient participation. To a certain extent, the features in myRecord allowed for the alignment of the patient's 'reality' (feeling anxious about symptoms of irregular heartbeats) with the clinician's 'project' of ensuring high quality telemonitoring (device settings are set properly, and the patient is notified in a comforting manner).

4.5. Principal findings

In concert, these four cases and the broader findings they represent inform our design rationale. MacLean et al. [36] were among the first to introduce the notion of *design rationale* in relation to the design of IT systems. Their idea was to deliver not just a system, but also "the argument behind the artefact." [36] Following this idea, we propose a design rationale for e-health services that are intended to involve patients as active participants (like myRecord). The design rationale is grounded in insights from medical phenomenology [18,23] and in analytical reflections from the participatory design and research of myRecord. We formulate a design rationale for e-health that we term *alignment of concerns*. The rationale accentuates the importance of making e-health services that align divergent needs and perspectives of patients and clinicians. It recognizes the decisive gap in how patients and clinicians conceptualise illness and disease and suggests the importance of working towards designing e-health services that specifically seek to reconcile their, often divergent, concerns. Below, we present three primary properties that are essential in identifying and subsequently aligning concerns and that need to be in place for patient participating e-health services to work. The properties are *meaningfulness*, *actionability*, and *organisational feasibility*.

Meaningfulness

This initial property designates how a concern of one party (e.g. the patient) can only become a concern for the other (e.g. the clinician) if it is found 'meaningful' by both, for instance by being acknowledged as clinically topical or relevant to the treatment and care process. Case 1 and 2 illustrate this by showing how concerns that are meaningful to Louis and Ben are not necessarily considered meaningful to the 'project' of the responding clinicians.

A meaningful concern is, however, no static entity. For instance, patients may experience that taking on 'clinical homework' using e-health services such as myRecord may result in more informed and more detailed answers that aid their own task of coping with the everyday

challenges of illness. That is, if patients begin to provide clinicians with the information they need in order to proceed in improved ways, clinicians may begin to consider the patient's concern as relevant and in turn begin to support the patient's needs. Still, concerns only align if they are found to be meaningful by both the patient and the clinician.

Actionability

In all four cases we pointed to the second required property for concerns to be aligned. Namely, that a concern is 'actionable.' Meaningful concerns arise as topical, clinically relevant and worth communicating about only when it is possible to take action on the concern. In other words, the concern needs to be actionable to come into consideration.

In the fourth case, myRecord facilitated the patient's articulation of a concern that proved relevant for both parties as it provided important information about symptoms not reflected in the ICD data. That is, the patient and the clinician succeeded, with support of myRecord, to make the concern actionable. By giving the lab technician the opportunity to quickly and easily respond verbally to the patient with a comforting message, a certain kind of action was made possible (an action of care, we might call it). In other words, the lab technician's (re)action made it meaningful for the patient to raise her concerns.

Organisational feasibility

A concern may be meaningful in the sense of relevant and actionable, but impossible to handle by the clinician receiving it (e.g. due to divisions in medical specialties and/or professional and organisational boundaries). With the third case we showed how a lack of knowledge about the infrastructure and distribution of care let the patient to raise concerns that were simply outside the scope of what the clinician could take action on. While myRecord succeeded in assisting the clinician in handling such a concern, by allowing her to quickly disregard it, the patient was not assisted in directing the *right concern* to the *right clinician*. As a result, the patient found his efforts and the e-health service meaningless. Hence, concerns put forth by means of an e-health service need to be 'organisationally feasible'. The concern must be actionable by the receiving clinician or the service should support the clinician in re-delegating action to the appropriate actor.

(See next page for Table 2)

Table 2 – Conceptual framework for aligning concerns in e-health

	Definition	Example
Meaningful	A concern is meaningful when it - at the same time - fits the biomedical model of medicine and the lived experience of patients	A patient addresses the cardiologist with a wide range of concerns that in number, character and style contrasts with what the cardiologist finds meaningful. The (lack of) response in turn makes the encounter meaningless to the patient.
Actionable	A concern is actionable when clinicians and patients are able to take appropriate action	A patient is concerned whether or not she has irregular heartbeat. The lab technician at the heart centre takes appropriate action by making a short reply where she explains and comforts the patient.
Organisational feasible	A concern is organisational feasible when clinicians are able to re-delegate action to the appropriate actor	A patient is concerned with his blood pressure and asks the clinicians at the heart centre to have it monitored. The request is, however, outside the scope of their responsibilities.

5. Discussion

In this section, we reflect on how our analytical insights and design rationale can be operationalized to support a development process and discuss implications for research.

5.1. Implications for designing e-health services

Turning to focus on *the process of designing* e-health services, we now unfold the generative potential of the design rationale and recommend important questions that a design team should seek clarification on at specific times in the process (figure 1).

Designing for alignment of concerns is a practical undertaking that requires prolonged interaction among stakeholders. It demands a process that goes beyond a traditional requirements specification process by an extended commitment to understanding users' perspectives [37] and engaging in collaborative design activities. When working with aligning concerns, it becomes a particular demand that the design process and the techniques applied are geared towards interworking *articulation* and *negotiation* of concerns. Seeking compromise and

consensus among stakeholders is highly important and it is not something that is achieved easily and in one go. As we have shown above, patients and clinicians have inherently divergent goals and focus on different aspects of illness and disease. Aligning concerns is an active, collaborative process and requires continuous translations and adjustments between what is regarded as meaningful and possible by various actors and thus needs to be supported locally and continuously in the process. Therefore, we first of all recommend a participatory design process where prospective users are actively involved throughout the project.

Participatory design methods [30,38] are tailored to connect divergent needs and concerns by co-designing technological solutions. Prospective users' active participation in the design process serves two purposes: 1) to create good conditions for the necessary mutual learning process among users and designers, and 2) for users to have a say, so that their concerns can be met by the future service [31]. Within health informatics, *co-design* is increasingly suggested as a way forward [26,27,39], involving research and design techniques such as ethnographic field studies, design workshops, scenarios, mock-ups and prototyping [see e.g. 40].

The participatory design process is typically organised in three phases: exploration, experimentation, and evaluation. We suggest treating these three phases as 'operational modes' in an *iterative*, rather than linear, process through which the potential for aligning concerns can be established and gradually realised. Figure 1 illustrates how designers can address *meaningfulness*, *actionability*, and *organisational feasibility* in each of the operational modes and thus iteratively work towards alignment of concerns.

Explore

It is worthwhile to begin with exploring questions such as: "*what are the main concerns?*", "*which actions are – or are not - taken to meet the concerns?*" and "*what are the responsibilities of organisational actors?*" This allows the design team to understand existing practices in all the relevant settings and to articulate and develop an in-depth understanding of the degree to which current concerns are meaningful, actionable and organisational feasible. The exploration should also involve engaging prospective users in prioritising and negotiating concerns. The design rationale 'alignment of concerns' serves as an analytical lens for exploration.

Experiment

As soon as the designers begin forming an understanding of the prospective users' concerns and their local contexts, they should start *experimenting* with new forms of IT support and new ways of organising treatment and care. The design rationale now serves as a generative theme, implying that the design team should start creating technical and organisational ways for both patients and clinicians to align concerns. This means *involving users in experimenting with "how concerns may become at once meaningful, actionable, and organisational feasible"*.

Often some form of negotiation is needed for one party to understand that in order to get what they want they have to do things that makes using the e-health service relevant for other parties. Sometimes this may simply not be possible, meaning that a *limit* to the potential of a given e-health service have been identified. In any case, supporting alignment of concerns entails giving shape not only to the IT system, but also to the organisational context and the work practices involved.

Evaluate

As the project evolves, new tasks, roles, and ways of cooperation emerge. At first we recommend that experiments are conducted in isolation from the daily practices of patients, relatives, and clinicians. The reason is to not do harm or violate concerns that the design team has not yet understood properly. However, as prototypes become mature enough, we suggest to cautiously test and *evaluate* in settings as close to real life as possible “*to see if concerns are aligned?*”. Ultimately this means trying out prototypes in patients’ homes and in clinicians’ work environments in order to evaluate the degree to which they are in fact meaningful, actionable, and organisational feasible.

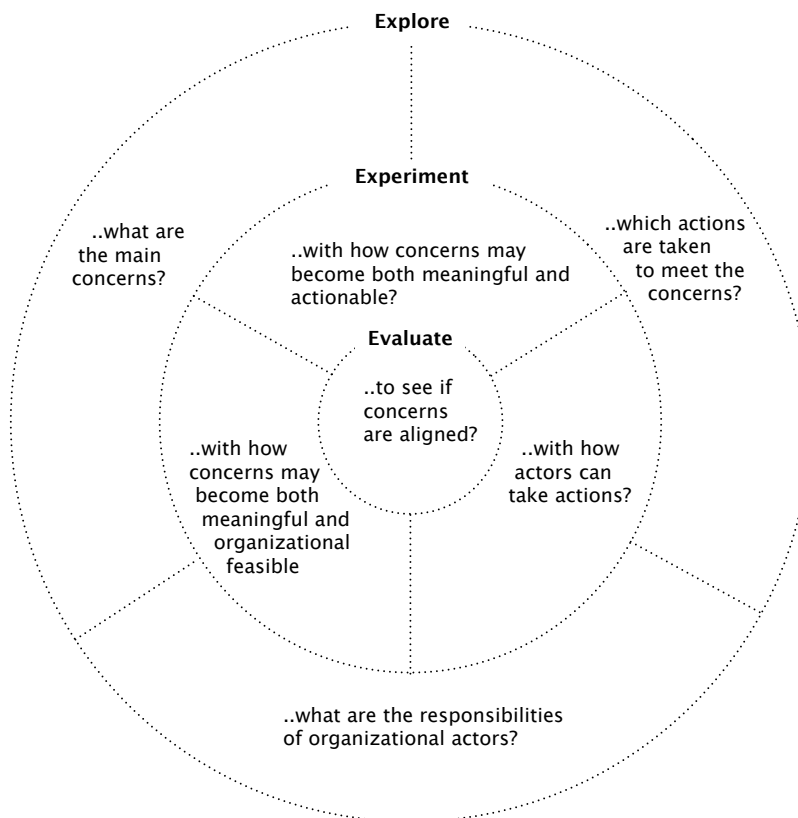


Figure 1: Model that illustrates three modes of activities that can become useful when designing patient-centred e-health services that support aligning concerns. It is based on the relation between the three concepts: *meaningful*, *actionable*, and *organisational feasible*.

5.2. Implications for research

While the design rationale and methodical approach presented is aimed at design of patient-centric digital services to support treatment of patients with a specific condition, there are strong indications that it will become increasingly important to align concerns between patients and clinicians in a wider context of healthcare. In this section we discuss the extended implications of the design rationale for research.

Several societal tendencies support the importance of enabling alignment of concerns among patients and clinicians. First of all, *multimorbidity* has, so to speak, become the most common chronic condition [41]. This means that more patients are at the same time treated for multiple, chronic diseases and often by different, specialized health professionals [42-45]. In practice, the challenge is therefore to ensure the *meaningfulness*, *actionability*, and *organisational feasibility* of a patient's concerns, not only with one clinician, but with a large, heterogeneous ensemble of organisationally distributed health professionals. This stresses the importance of supporting patients and clinicians in aligning their concerns. To fully anticipate the consequences of multimorbidity, some questions regarding alignment of concerns remain to be explored: In cases of multimorbidity, the patient will often interact with several communities of highly specialised health professionals, potentially with different concerns. What is meaningful, actionable, and organisationally feasible may therefore differ, making alignment of concerns all but a mundane task. It is therefore important to investigate how concerns can be aligned in cases where the patient interacts with a heterogeneous community of health professionals. Also, as traditional health management programs typically focus on single conditions and do not stipulate interactions between combinations of chronic disease, it is common that care interventions intersect and produce cross-effects, some unforeseen [46]. Therefore, it is of crucial importance to investigate the need and potential for aligning concerns among different groups of clinicians as well and to explore how this can be accounted for in a design rationale.

Furthermore, the appropriateness of traditional biomedical treatment goals is increasingly being discussed. For instance, in the emerging discourse on *goal-oriented care* [47], the traditional biomedical model of *problem-oriented care* is criticised for a lack of concern for the patient's desired outcomes and for a lack of ability to support coordination between different courses of treatment. In the problem-oriented approach, therapy is mandated using condition-specific indicators and a guideline designed to achieve a certain target [48]. In contrast, in a goal-oriented approach care is mandated by functional goals defined by the patient, for instance regarding symptoms, physical functional status, and mobility [47,49]. A goal-oriented approach will require more extensive involvement of patients' perspectives, and it will become even more important to render their concerns *meaningful*, *actionable* and *organisationally feasible* for the clinicians. While it is beyond the scope of this article to propose how this can be accounted for in design of digital services, we recommend the methodical approach outlined in section 5.1 as a framework for further investigations.

6. Conclusion

With this article, we have sought to provide a reflexive analytical framework for designing patient-centred e-health services. We started out by recognizing the shift from hospital information systems to e-health and the new challenges that arise when extending the healthcare network to include patients as active, participating users. We then presented important insights from medical phenomenology regarding the general differences between patients' and physicians' perspectives, suggesting that it is crucial to take these insights into account when designing and evaluating e-health services. With this conceptualisation as our analytical point of departure, we unfolded four cases from the design and user tests of a working prototype, myRecord, demonstrating the implications of patients' and clinicians' different concerns and the need for appropriate alignment of these. That is, when designing e-health services to support collaboration between patients and clinicians, it is important to identify the concerns that are *meaningful* to both patients and clinicians and, moreover, which concerns are or can be made *actionable* and *organisationally feasible*.

With our analysis, we first of all brought forth the consequences of introducing e-health into existing care networks and how it complicates care. However, we have also demonstrated how e-health provides opportunities for new forms of care where active patient participation improves clinical decision-making and the quality of healthcare. Introducing a personal health record for ICD patients and the involved professionals turned out to reproduce, and even underpin, existing challenges of empowering patients to engage more actively in chronic care. With one version of myRecord, featured in the first three cases, the decisive gap between patients and clinicians was made more tension-filled and dissatisfactory for at least one part, often the patient. In these cases, the e-health service neither tapped into nor succeeded in supporting the alignment of concerns between patient and clinician. More specifically, myRecord failed due to a persistent mismatch between the respective patients' and clinicians' perceptions of what constitutes a meaningful concern and subsequently appropriate action. With the final case, however, we showed how the service succeeded in aligning concerns by facilitating a translation of the patients' concerns into clinically meaningful issues *and* making them clinically and organisationally actionable.

The somewhat contradictory outcomes of the design and use of myRecord illustrated by the different cases only underpin the necessity of developing solid and empirically grounded design rationales for e-health, as we believe the design rationale put forth in this paper - *alignment of concerns* – to be. Echoing research that suggests participatory design (and co-design) as a way ahead [26-28], we recommend to operationalize the design rationale by engaging in participative design activities that employ a strategy of iterating between exploring, experimenting, and evaluating to enable the necessary collaborative process of identifying and negotiating concerns. The fact that the heterogeneity of patients' and clinicians' perspectives in practice may be even more complex than indicated by classic medical phenomenology only

stresses the importance of approaching the alignment of concerns as a participatory and iterative process.

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